QUALITY OF LIFE AND DEINSTITUTIONALISATION : AN EXAMINATION OF THE EFFECTS OF RELOCATING PEOPLE WITH LEARNING DISABILITIES FROM HOSPITAL TO LIFE IN THE COMMUNITY

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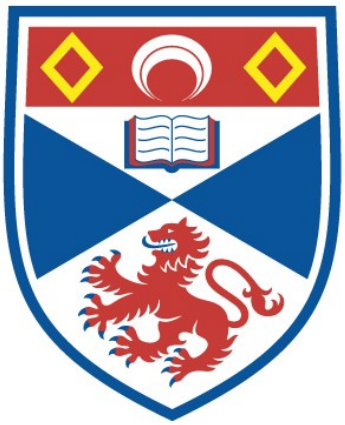

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QUALITY OF LIFE

AND

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An examination of the effects of relocating people with learning disabilities from hospital to live in the community.

A thesis presented for the degree of

DOCTOR OF PHILOSOPHY

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MARGARET WHORISKEY

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ABSTRACT

The quality of life for people with learning disabilities was examined for 50 people leaving hospital to live in a range of community residences and for 50 people remaining in hospital. Individuals were followed up for up to 30 months at six monthly intervals.

The social validity of quality of life assessment was examined by comparing the importance of a number of service objectives to people with and without learning disabilities. This then informed the development of two measures used to assess aspects of quality of life.

A range of measures were employed to address both objective and subjective dimensions of quality of life. Five main areas were identified and examined in two studies - competence and personal growth; health and well-being; quality of care; engagement in activity and staff resident interactions. The issues reflecting some of the difficulties in assessing subjective states of people with learning disabilities are discussed.

Overall there was some relatively small changes in the areas of competence and personal growth, quality of care and staff interactions for people moving from hospital to live in the community. The changes tended to occur within six months of moving with little improvement thereafter. In general, there was no change for the people remaining in hospital. Implications for the detailed examination of the effects of deinstitutionalisation are discussed.

Declaration

I Margaret Whoriskey, hereby certify that this thesis, which is approximately 100,000 words in length, has been written by me, that it is the record of work carried out by me and that it has not been submitted in any previous application for a higher degree.

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For Neil, Amie and Megan,

and the memory of their Papa Jim, and Granpa Neil.

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CHAPTER 1

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Introduction

The Context

Surprisingly, given the number of institutions closed and closures in progress, there has been relatively little research or literature related to deinstitutionalisation (Lynch, Fellow and Willson,1997) Most of the literature available is qualitative or commentary in nature. Relatively little quantitative data regarding the effects of deinstitutionalisation has been collected.

The recent history of services for people with a learning disability has been characterised by dramatic shifts from a medical, segregated, institutional paradigm through a developmental deinstitutionalised model to an emergent community membership and functional support model (cf Hatton 1998). The history of service evaluation has undergone similar shifts.

There is a need to examine the historical background to the process of deinstitutionalisation and to consider the many factors that have influenced progress to date. The present study approaches the area by focusing on the lives of people with a learning disability and the impact of deinstitutionalisation on them.

Deinstitutionalisation - The Concept

Deinstitutionalisation is a relatively modern concept and inevitably came into being in the context of institutionalisation. Myers and Clacher (1987), in their review of anthropological literature, found no mention whatsoever of any residential segregation or seclusion of people with learning disabilities.

During the second half of the nineteenth century the Victorians turned their energies and reforming zeal to the facilities for those suffering from mental disorder. They built a series of large hospitals on the outskirts of centres of population. Now, in the second half of the twentieth century all this is being reversed.

In their review of the subject Shinn and Felton (1981) noted that "Deinstitutionalisation, surely one of the largest catchwords in the English language, has become a national priority for deviant and dependent populations". The authors identified that the rhetoric supporting deinstitutionalisation is similar for the mentally disabled, criminal offenders and the aged. There are important similarities in deinstitutionalisation efforts for these three groups. There are similarities in conceptual problems such as defining what it means for an alternative programme to be community based; in ethical issues such as balancing the needs and rights of members of the target population; in research issues such as selecting criteria for evaluating programmes; and in practical issues such as overcoming community resistance.

The label deinstitutionalisation has been applied to the shift in emphasis from large custodial facilities (Bradley, 1976). The deinstitutionalisation movement, at times, has been seen as an end in itself and although it has called attention to the indignities of institutional care, it has failed to conceptualise alternatives (Bennett and Morris, 1983). The aims of this movement are broader than that of simply returning residents to the community from the institution. Scheerenberger (1976) has suggested that prevention of inappropriate admissions and institutional reform must also be targets if deinstitutionalisation is to be successful.

The rundown of big 'institutions' for persons with mental illness preceded this similar trend for people with learning disabilities. Deinstitutionalisation in Britain is usually dated from the mid 1950s when the populations in the large mental illness hospitals started to decline. The last three decades have witnessed marked changes in residential services in the U.K. for people with learning disabilities mirroring changes which have occurred in North America and Western European countries (Emerson et al, 1996; Emerson and Mansell, 1996). The U.K. has seen a marked reduction in institutional provision and a corresponding increase in community based services for people with learning disabilities.

From the late 1950s community care became the objective but 20 years went by before a major hospital closure was contemplated and nearly 40 years before it was achieved. The movement towards deinsitutionalisation began largely as ideology and has taken many years to translate into practice.

There have been a number of significant policy documents which have given the impetus for change.

Since the publication of the white paper "Better Services For The Mentally Handicapped" (DHSS 1971) there has been a steady movement towards the reduction in the number of people with learning disabilities living in hospitals. This has been achieved by preventing admission to such hospitals and by discharge policies (assisted in the U.K. by the provision of government bridging finance schemes) which enable community services to be developed before funds are released.

Throughout the 70s and 80s there were a number of developments which led to the conclusion that moving people with disabilities from hospital to community settings would be a desirable goal.

Reduction in hospital numbers between the 1970s and early 1980s was mainly brought about by reducing long term admissions, particularly of children and through death among the elderly hospital population. Very small numbers of residents actually moved out of hospital during that period. Money was still going into improving and replacing existing NHS provision with hospital units of 70 to 100 or more beds as a favoured model.

The 1983 circular "Care in the Community" (DHSS, 1983) led to the further development of community placements in the U.K. One aspect of this development was the funding, by top slicing DHSS joint finance money, of a series of Care in the Community pilot demonstration projects at selected sites around the country (not in Scotland) (Knapp et al, 1992).

During the 80s and early 90s the capacity of hospitals for people with learning disabilities in the U.K. was further reduced by over 26,000 places (Emerson and Hatton, 1994). During this period of transition thousands of people with disabilities have moved from such hospitals to a range of community settings.

Planned closure programmes preceded the implementation of the 1990 NHS and Community Care Act but have gained momentum with the formalisation of the enhanced role of local authorities. In 1973 70% of the remaining hospitals in England had been identified for closure (Greig, 1993) and in Scotland a similar trend has merged with a number of hospitals scheduled for closure by the turn of the century although not at the same pace as south of the border.

As the deinstitutionalisation programmes are now well underway throughout industrialised nations it has become clear that neither the rhetoric of deinstitutionalisation, nor the movement of persons from one setting to another by themselves, leads to a better quality of life, more effective provision of services or better outcomes for the people affected (Emerson and Hatton, 1994; Shinn and Felton, 1981; Lynch, Kellow and Wilson, 1997) Deinstitutionalisation is being taken up with the same fervour, rhetorical conviction and lack of experience that the institutional solution received in its time (Korman and Glennerster, 1990).

Learning Disabilities - The Rise and Fall of the Institution

In dealing with the issue of deinstitutionalisation one must first examine the development of the institutional model and the evolution of services for people with learning disabilities over the years.

Institutions for people with learning disabilities were set up in the last century with the positive aims of providing protection from exploitation within the community and giving education and training for suitable occupation.

Throughout history, the attitudes of society towards people with learning disabilities have vacillated extensively. At one time or another they have inspired feelings of dread, reverence, menace, charity, obligation and love (Kanner, 1964; Wolfensberger, 1976). The type and quality of care and treatment given to the learning disabled by society at any point in history, reflects the prevailing attitudes at that time (Doll, 1972).

The rise of the large institutions was apparently the result of the new "humanism", the new responsibility, the new optimism towards the training of the developmentally disabled which arose in Europe and the United States during the late 18th century and flourished through most of the 19th century (Doll, 1972; Kanner, 1964).

In the United Kingdom the 1890 lunatics act made the establishment of asylum by county authorities compulsory for those of unsound mind and for the mentally subnormal.* The Act was concerned with the legal status of the person and the regulations governing admissions, detentions and discharge. There are differing interpretations as to why asylums became a statutory obligation from a humanitarian standpoint. Jones (1960) considers the development of asylums as a reaction to poor conditions in workhouses and private mad houses. In describing the lunatics act of 1845, Jones writes that "Ashley and his colleagues had roused the conscience of mid-Victorian society and had set a new standard of public morality by which the care of the helpless and degraded classes of the community was to be seen as a social responsibility" (p149).

An alternative explanation is provided by Scull (1979) in *Museums of Madness.* He argues that institutions were the outcome of urbanisation, industrialisation and professional forces that developed during the first half of the 19th century.

* While the use of the term learning disability is the term of choice, and is referred to throughout the document, other terms are used in the context of the historical development of services such as mentally subnormal, mental defective, mental retardation.

It was an economic necessity to separate those who could not work from those who could and therefore should.

For people diagnosed as 'mentally deficient', the supposed link between mental deficiency and social problems - criminality, promiscuity - led to discussion of the need for sterilisation and the segregation of people. It strengthened the case for institutional care. These views were widely held in the last quarter of the 19th century and were based on what are now seen as suspect scientific claims advanced largely through the work of Sir Francis Galton and authors of several studies of hereditary behaviour in families (Jones, 1960).

Guggenbuhl's founding of the Abendberg in 1841 marked the beginning of segregated residential facilities for people with learning disabilities. This became an international model of institutional/residential training for retarded children, combining both medical and educational practice. In the USA Samuel Howe greatly inspired by a visit to the Abendberg in 1848, was instrumental in the development of the first institutional facility for young people with mental retardation in Massachusetts in 1855. The focus of the institutional facility was educational.

Once established, institutions experienced pressures to grow (Wolfensberger, 1976). Their original intent, to habilitate the mentally retarded, was often frustrated by parent, professional, and public pressures to prevent re-entry of the handicapped into the community.

In the UK the government set up a Royal Commission on the care and control of the feeble minded (1904 - 1908) to examine the issues of segregation and sterilisation. The commission concluded that although heredity played some role in mental deficiency, and though mental deficiency was linked to some social problems, this was due to the freedom allowed to 'mental deficients' in the community. The commission favoured a more stringent system of ascertainment and supervision which would protect the 'mentally deficient'

person. The commission rejected a policy of sterilisation. Its report laid the foundations for the 1913 Mental Deficiency Act, which recommended that each local authority establish a "colony" as a basis for specialised custodial care. This would provide a completely self-contained and segregated environment where mentally deficient people of all ages could live, train, work and relax with villas for residences, schools, workshops, churches, recreational facilities and farms. The first world war intervened to delay the construction of such colonies until the 1920s and 1930s.

The 1913 Mental Deficiency Act defined mental deficiency primarily as a social condition (in terms of idiots, imbeciles, feeble minded and moral defectives). This definition lead to greater discussion and recognition of the problems and to further social and medical research.

With the growth in institutional facilities it was still recognised that there was a large number of people with mental deficiency capable of living a normal sociable life within the community under some form of supervision. The Wood Committee, established in 1929, made a distinction between primary and secondary amentia as causes of mental deficiency and thought only those whose mental deficiency was based on a primary cause, such as inherent genetic defects, who represented the lowest tenth of the population, needed to be segregated. Even those requiring care in segregated institutions needed care which would prepare them for life in the community (Jones, 1960). The committee again stressed the importance of the development of purpose built colonies as the best means for caring for mentally sub-normal people.

The period between the two wars saw the rapid expansion of specialised institutions for the mentally handicapped. Starting with 2,040 such people in special institutions in the UK in 1914 by 1961 there were approximately 61,000 people in hospitals. The number peaked during the mid sixties to about 64,600 (Bone, Spain and Fox, 1972).

The Reaction Against Institutions

In 1919 Fernald published his famous Waverly Studies in the USA. These studies involved follow up of residents released over a 25 year period from institutions in the USA. Fernald, was one of the strongest supporters of segregation and of the social menace conception of the mentally retarded. However he greatly modified his position and concluded that many could be safely returned to the community if their families were able to look after them and give them proper supervision (Fernald, 1919).

Anderson (1922), Wallace (1929) and Wallin (1924) all presented studies showing that the retarded were not necessarily destined to develop into criminals.

Despite the empirical evidence supplied by Fernald and others, the social menace image of the mentally retarded persisted. However from 1914 to 1939 ideas had gradually changed about the care of mentally deficient people. There had been a swing away from the concept of permanent detention towards the growth of care in the community (Jones, 1960).

In the USA the parole plan developed in 1922 provided for the release of suitable individuals to the care of their parents, relatives, volunteers or employers under the continuing supervision of the institution social worker. Other forms of care were being provided and the 1930s saw the introduction of family care models for the mentally retarded, under which the state would pay for the maintenance of retarded persons in a home other than their own. Hubell (1941) described a system of care somewhat resembling the group homes of today. Also a variety of "colonies" evolved - farm colonies for men located in rural regions, industrial colonies for men and women located in towns where the residents worked in factories and mills or did odd jobs, and domestic colonies for the women.

It is therefore clear that alternative models of care were being developed in the early part of this century at the same time as institutions expanded. Social climate was changing slowly in that people with mental deficiency were not all viewed as criminals and insane.

Just as the history of institutions is an interplay between the medical profession, public morality and political/economy, so too is the story of deinstitutionalisation. Professional and public attitudes, scandal and the growing cost of maintaining these institutions began to produce a change in political perceptions. As the centenary of many of these institutions came and went the question of what to do with the out-dated buildings and their increasingly valuable sites forced itself on to hospitals' and then health authorities' agendas. The conversion of many military facilities and tuberculosis hospitals to mental retardation institutions in the 50s and 60s had apparently swelled the state's institutional inventories beyond what was needed. In 1951 the recession arrived and many facilities became expendable.

The trend of moving people with learning disabilities out of institutions and into community settings is attributable to several factors as noted above.

Two assumptions are primary for most deinstitutionalisation rationales:

- Institutions do not engender client growth and
- Community settings provide greater opportunity for development in more 'normal' environments.

In relation to the first assumption a number of factors influenced this belief including research evidence on the detrimental effect of institutions, human rights concerns, and problems with the conditions in long stay institutions.

The second assumption developed from this along with the recognition that people with a learning disability were capable of learning.

Each of these assumptions are examined below.

As Watson's behaviourism became increasingly influential in American psychology, it is not surprising that a view began to emerge that institutions offered very little stimulation for intellectual and social development.

The notion that institutions are detrimental to client growth dates back to early studies on the impact of maternal and sensory deprivation. Zigler (1978) proposed that residents of institutions rarely have nurturing or meaningful interaction with adults and as a result, are dependent and suspicious. Research supports Zigler's perspective (Balla, Butterfield and Zigler, 1974; McCormick,Balla and Zigler 1978) with evidence that institutions have similar effects on 'non-retarded' persons (Zigler 1963). A number of investigators examined behavioural correlates of institutionalisation. Butterfield (1967), Heal, (1975), McCandless, (1964) and Scheerenberger (1976) have reviewed these studies. The literature is reasonably consistent in that it indicates that commitment to an institution often occasions a decline in IQ scores (Crissey, 1937; Kaplan, 1943; Sternlicht and Siegal, 1946).

However other researchers did not paint such a bleak view of institutions. If the pre-institutionalised environment was extremely impoverished some improvement in level of functioning were found for some people (e.g. Clarke and Clarke, 1953; Clarke, Clarke and Reiman 1976). These findings lent support to the construction of the institution contrasting to the serious concerns being expressed at the same time about the detrimental effects of institutions. Most of the studies attempted to find ways of making hospital care more effective

Thus both the champions and the challengers of the institution can cite empirical support for their cases. The assumption that institutionalisation is, without qualification, detrimental to client growth is too simplistic.

It is recognised that institutions have many different characteristics that may affect residents in various ways and institutions should therefore not be treated as one variable.

A more direct assault on institutions, and on mental hospitals in particular, began in the early 1950s. One of the earliest issues concerned not conditions in institutions but the loss of liberty suffered by those wrongfully certified and detained. *50,000 Outside The Law* (NCCL, 1951) argued that mentally subnormal people lacked some of the legal safeguards available to the mentally ill against wrongful detention. Conditions in mentally deficiency institutions created "a vested interest" in retaining people rather than releasing them. Patients often did work which would otherwise require additional paid staff and hospitals took on commercial work without adequately paying patients. The pamphlet demanded a revision to existing law to prevent such conditions, and contributed towards the setting up of the Royal Commission on Mental Health in 1954.

The frontal assault on the underlying ideology of asylums was made by Goffman (1961). He analysed the social structure of institutions and the relations between inhabitants and staff, and introduced the influential concept of the

"total institution". The central feature of a total institution was said to be a breakdown of the barriers found in ordinary life normally separating the place to live, the place to work and the place for recreation.

Similar ideas were developed in England by, for example, Russell Barton (1959) in an extremely influential book on Institutional Neurosis. Criticisms of 'mental' hospitals in the U.K. were less strident and less condemning than those in America but, nonetheless, by the end of the 1950s and early 1960s progressive thought in psychiatry was rapidly moving away from hospital as a base for care of people with mental illness towards provision in the community. The attack on institutions was not confined to mental hospitals. Other types of institutions came to be seen as tarred by the same brush. Townsend (1962) carried out surveys of institutions for the elderly in England and Wales. Over half of new admissions, he claimed, were physically and mentally fit to lead independent lives. The overall impression gained was one of social isolation, poor physical environments and institutional management regimes.

A similar study of institutions for people with a learning disability was produced seven years later by Morris (1969). A comparable depressing picture emerged of meagre and inappropriate conditions with only a minority of residents seeming to need hospital care.
The description of the 'back ward' by Jones (1960) painted a grim picture of overcrowding, neglect and in some cases outright brutality.

The concern that deleterious effects were inherent in what Goffman (1961) had termed "total" institution has grown and seems to be confirmed by the documentation of dehumanising conditions and accommodation in large facilities for people with learning disabilities both in the U.K. and the United States (Shearer, 1968; Morris, 1969, DHSS, 1969, House of Commons 1974). This and other work identified the poor conditions and revelations of cruelty in long stay institutions in Britain.

Reports of enquiries set up to investigate allegations of ill-treatment became a feature of social policy literature during the 1970s (Ely Hospital, DHSS, 1969; Normansfield - DHSS, 1978). They presented a catalogue of failure at all levels of service provision and service management (Martin, 1984).

In his analysis of reports by committees of enquiry into 19 hospitals, Martin cites common features found in these hospitals which more or less mirrored the studies of hospitals in the 1950s: geographical and professional isolation; abandonment of patients by their community; lack of support towards staff; failure of leadership among all professional groups and "corruption of care".

The public enquiry reports noted that such extreme conditions tended to be confined to certain wards, particularly those with the most dependent and disturbed residents. Staff were few in number and lacked the training and experience to provide adequate care. In general, the least rewarding residents, although they generated the greatest need, tended to be given the fewest resources. As Wing notes (1989) "the irony was that the deplorable conditions suffered by many handicapped people in the community, which led to the setting up of the institutions, were eventually reproduced within the institutions themselves" (p 2).

Thus by the 70' and 80' there was sufficient evidence from a range of sources to support the assumption that institutions do not engender growth and in fact can have a serious detrimental consequences for people with learning disabilities. Important research studies, initially showing the considerable abilities of many adults living in large institutions, (O'Connor and Tizard, 1956) and confirming that people with severe learning disabilities are capable of learning (Clarke & Hermelin, 1955), directed attention to the possibility of alternative services. Developing from this premise was the assumption that alternatives to institutional care would provide greater opportunities for people to develop and participate in normal community life.

In England, the Brookland Study (Tizard, 1964) demonstrated that some severely mentally handicapped children who lived in a community facility for up to 3 years developed favourably compared to similar children who remained in hospital. Developing from this work, King, Raynes & Tizard (1971) found care practices to be more resident-orientated in small group homes and more institution-orientated in large hospitals.

Thus, at the same time as criticisms of large central institutions had been voiced, a substantial case for alternative community-based services has developed.

The change in the pattern of service provision has been relatively slow and what new provisions were developed initially concentrated on the most able people in care with an assumption that the severely and profoundly handicapped people should be cared for in a hospital setting. The use of small residences to meet the housing needs of the most severely and profoundly mentally handicapped people remained an issue. For example, the State of Alabama Department of Mental Health Professional Advisory Committee stated that "we believe that complete deinstitutionalisation is impossible, given the extreme debility of the remaining institutional residents, after the most able and healthy residents are first selected for community living" (Balla et al, 1979). The inference from such a statement is that the level of support that has been provided by the service agency for the most heavily handicapped people cannot be provided in community settings.

The case that the large hospital model is the only practical and economic way of organising residential care for severely and profoundly mentally handicapped people is recognisable in the writings of many medical and nursing experts and bodies (e.g. Royal College of Psychiatrists, 1976; Royal Medical-Psychological Association, RMPA, 1971; Shapiro, 1970). The view that some services can only be provided in a hospital were shared by groups such as the National Development Team and National Development Group (cf Kings Fund 1980). However, at least in part, these positions are caused by confusion between the question of which agency and professional staff should provide residential

services to people with learning disabilities and the questions concerning the optimal size, location and organisational requirements of residential services.

Despite the volume of opinion and support and then criticism of a "community care service model" on the one hand and a "large hospital model" on the other, there have been few systematic investigations into the feasibility and quality of alternative ways of organising residential care. Alternative services for learning disabilities were under researched in comparison with mental illness. This perhaps reflected a belief dominant in the early part of the century that nothing could be done. The considerable change in attitudes towards mental illness seemed to pass by services for people with learning disabilities (Korman and Glennerester, 1990).

The Policy Context

By the late 1960s a broad political consensus had begun to emerge that something ought to be done about the large, long stay hospitals for people with learning disabilities. In 1969 there were approximately 49,200 adults and 7,100 children in hospital care (DHSS, 1980). Under the combined impact of the Ely enquiry, Barbara Robb's campaigning skills and Pauline Morris's survey (Morris, 1969), people with a learning disability were established for the first time on the national policy agenda. Richard Crossman, Secretary of State, set aside a capital allocation to encourage regional hospital boards, as they then were, to improve long stay facilities. Work began in the Department of Health and Social Security in the mid 1970s to prepare a national plan to develop services for people with learning disabilities, not just within the National Health Service, but by the local authorities.

Better Services for the Mentally Handicapped (DHSS 1971) was the first detailed comprehensive guidance to be issued for any client group by central department, and it became a model for subsequent white papers on the mentally

ill (DHSS 1975) and the elderly (DHSS 1981). The main objectives were to bring about a reduction of about one half in the number of hospital beds provided for people with learning disabilities and to expand local authority places in residential homes, training centres, foster homes and lodgings. The policy outlined a programme for the development of these local services and indicated the reduction in size in the existing institutions. However, little thought had been given to the meaning of community care and little attention paid to the notions of integration to ordinary settings, relationships or employment. The assumption was that the more able residents would become the responsibility of local authorities, and the more severely handicapped would remain in hospital, although in rather smaller and more modern ones.

By 1974, only about half of the places in centres for adult training and occupation estimated to be needed in the community had been produced and about a third of the residential facilities. There were still some local authorities who made no provision at all (cf Abel-smith, 1978). Overall, while the concept of community care sought to enhance the quality of life, while seeking to reduce expensive hospitalisation, the organisation had proved less than effective due to under resourcing in the community services.

The Jay Committee on Mental Handicap Nursing and Care, in its report published in 1979 recommended a model of care based outside hospitals in small local units to enable people with learning disabilities to live a normal life within the community (Jay Report DHSS 1979). It incorporated many of the ideas of normalisation and the emphasis was on providing support for families with a learning disabled member. Where alternatives to family or foster care were necessary the emphasis was on the provision of small, highly staffed units or on conventional housing. There was no place for the traditional long stay hospital.

The Committee was not unanimous in making this recommendation and debate continued as to whether certain groups, especially adults with severe handicaps,

required hospital care but financial restraints made any rapid movement towards the Jay model unlikely.

By 1980, a DHSS review of services for the 'mentally handicapped' (DHSS 1980) indicated that progress had been made in meeting the objectives of the policies set out in the 1971 white paper, Better Services for the Mentally Handicapped (DHSS, 1971). The 1980 review showed that the number of adults in hospital had fallen by over 5,000 although at a slower rate than envisaged and that places in local authority training centres and residential homes had correspondingly increased.

By 1981 a consultative document, Care in the Community (DHSS, 1981), estimated that 15,000 mentally handicapped people, including 2,000 children, were living in hospital and about one third of the total could be discharged from hospital if community services were available. A number of proposals for transferring patients and resources from hospitals to the community were discussed (DHSS, 1981).

The All Wales Strategy, launched in 1983, was an attempt to implement the principles articulated in the White Paper (DHSS, 1971), Jay Report (1979) and built on the work an earlier community care model known as the Nimrod Service (Welsh Office, 1978). They took a noticeably different direction to the rest of Britain by assuming a larger measure of direct control over local development.

In later policy guidance the DHSS (1985) said "Health authorities should aim to accommodate eventually in small, homely units based in local communities, all mentally handicapped people requiring care in a health setting, except possibly some special needs". This statement essentially spelt the end for the long stay hospital for people with learning disabilities.

Despite the fact that hospital closure was now a high priority for health authorities, public doubts remained. The Houses of Commons Social Services Committee in 1985 published a very influential report (House of Commons 1985). This represented the first official evidence of some backlash against hospital closure, not least a more wary attitude to the pace of hospital closure, and fears about the level of alternative provision that was being made. "Asylum can be provided in a physical and psychological sense in the middle of a normal residential community setting but we must face the fact that some people need asylum" (p 26). The committee pointed out the importance of proper evaluation of hospital closures.

The organisation of services for people with learning disabilities are undergoing a period of major transition resulting from the implementation of the 1990 NHS and Community Care Act. The separation of purchasing from service provision, the enhanced role of local authorities and the independent sector and the introduction of new arrangements for monitoring services have all helped to create new opportunities and new threats to the development of services for people with learning disabilities.

By 1992 the rate and pace of deinstitutionalisation across the UK varied considerably. The English institutional population had dropped to 44% of its 1980 level with proportionally larger institutional populations remaining in Wales (53%), Scotland (57%) and Northern Ireland (70%) (Emerson and Hatton, 1994). Similarly the nature of the services developed in the community to replace hospital provision has varied over time and across locations. The first wave of deinstitutionalisation in the UK involved the move of those individuals with the least serious disabilities to a range of often pre-existing services including hostels, semi-supported group homes, family placement schemes and independent living (Korman and Glennerster, 1990; Malin, 1982).

During the 1980s, however, attention switched to the development of community based residential provision for people with more severe disabilities, including

those with additional needs such as sensory impairments or 'challenging' behaviour (Blunden and Allen, 1987; DHSS, 1984; Department of Health, 1989; 1993).

The last two decades have seen the coming together of two philosophies guiding social policy relating to services for people with learning disabilities. One considers the right to habilitative treatment and three areas have had a definite impact on this concept:

(i) research demonstrating the active and deliberate programming to alter the behavioural functioning of its recipients (e.g. Berkson and Landenman-Dwyer, 1977);

(ii) in the United States court cases (Wyatt versus Hardin) upholding the right to habilitation; and

(iii) standards for judging service provision e.g. (National Development Group, 1978, 1980).

The second development has been the right to live within a residential community, and this derived momentum from proponents of normalisation and deinstitutionalisation. Thus, there has been a rejection of large institutional care in favour of smaller facilities which approximate ordinary housing (e.g. Grunwald, 1986; Wolfensberger, 1972).

The Normalisation Ideology

While the early empirical results have encouraged those who would like to develop residential alternatives to the large, state supported facility, the course of history has more pressing spurs than empirical information. A most impressive influence on the evolution of residential alternatives for people with learning disabilities has been the parent associations that were formed throughout the world following World War 2 and the normalisation driven ideology (Wolfensberger, 1972).

The term 'normalisation' has now been in use for over three decades. During this period it has proved to be an influential concept in debates concerning the most appropriate way of providing services for people with learning disabilities in Scandinavia (Grunewald, 1986), North America (e.g. McCarver and Cavalier, 1983) and the U.K. (e.g. Tyne, 1987, 1989). More recently this influence has broadened to include other disability groups (Emerson, 1992).

Normalisation offered a theoretical model from which to develop good practice. In particular it offered a way of conceptualising the pull towards negative practice and an important model of how to reverse this (Brown and Smith, 1992).

Throughout the 1960s the notion of normalisation had a considerable impact on the development of services for people with learning disabilities in Denmark and Sweden (Nirje, 1970). The early Scandinavian formulations of normalisation are straight forward in that they advocate that services should seek to maximise the quality of life of service users by reproducing the lifestyle experienced by non-disabled citizens. Normalisation is about rights, and as such, requires no specific justification.

The normalisation principle was quickly translated to the American scene as a working philosophy of reform. However when the normalisation principle was adopted for American use, an important change occurred. The Scandinavian perspective of normalising the physical and social environment was attached to an American expectation that the behaviour of residents would become more normalised. Thus, the purpose of institutional reform was not only to move from custodial to normalising environments but also to engender more "normal" behaviour among residents (Wolfensberger, 1972).

The successive reformulations of the principle of normalisation have been elaborated through the development of a series of evaluation materials whose primary use lies in assessing the extent to which services implement the principle

of normalisation (Wolfensberger and Glenn 1973 & 1975 and; Wolfensberger and Thomas 1983).

The introduction of normalisation into the UK followed the series of enquiries into conditions amongst institutions during the late 60's and 70's. The Scandinavian formulations of normalisation were influential in terms of shaping ideas, on the design of new services and the remodelling of old institutions for people with learning disabilities (e.g. Gunzberg, 1970).
In the 1970s a number of alternative models to the large hospital were developed. These included:

> the Wessex. model which was established to provide residential services for severely disabled people in locally based units of 20 or so beds; and the 'community unit' model whose concept emerged from a series of papers by the National Development Group and Development Team (DHSS 1977). The philosophy of care underpinning this model was one of an action resource centre which may provide temporary or permanent accommodation for children and adults for long or short periods of time.

While these new models of care marked a departure from the old institutional model there were concerns that while showing evidence of improved 'quality of care' the size and location of the units means that they were not well integrated in local communities (Kings Fund 1980). It was also felt that there was a lack of clarity about key points of principle.

Around this time the focus on normalisation and its' applicability to service delivery was receiving considerable attention.
Tyne (1982) summarised the principle as :-
.....firstly, helping handicapped people to gain skills and characteristics and to experience a lifestyle which is valued in our society and to have opportunities for using skills and expressing individuality in choice;
secondly, regardless of people's handicaps, providing services in settings and in ways which are valued in our society and supporting people to participate

genuinely in the mainstream of life. This includes taking risks, carrying responsibilities and making choices;
thirdly, by helping society to be much more accepting of people's differentness.

Much of the inspiration for this alternative principle of 'normal living' came from services developed in Nebraska in the U.S.A. and published in Britain by the Campaign for Mentally Handicapped People (1978) and the Kings Fund (1980).

The influential report An Ordinary Life (Kings Fund 1980) identified key principles based on the normalisation philosophy. These were

- people with learning disabilities have the same human value as anyone else
- living like others within the community is both a right and a need
- services must recognise the individuality of people with learning disabilities.

The philosophy of service provision identified in this report was based on the Encor model of care in the U.S.A. Eastern Nebraska Community Office of Retardation (cf Thomas, Firth and Kendall, 1978) whose aim was to provide a comprehensive community service for all people regardless of their level of disability where the client and families live.

The ordinary life model supported a 'core' and cluster approach to the provision of services in normal family type accommodation.

Over the last 2 to 3 decades there has been a steady lowering of the number of residents considered appropriate within one living unit. Wards and hostels with 50 or more residents were once accepted. Later units of around 20 to 25 people were advocated. Now in response to a philosophy of normalisation, living groups with the size of the average family and the reference community have become the theoretical ideal of many workers and policy makers in the field. Together with the downward trend in views of numbers of residents, there has been an increasing preference for a domestic, individualised style of housing and furnishings. The use of ordinary houses in ordinary streets, well separated from

each other, has been advocated as a way of ensuring normalisation (Menolascino and McGee 1981).

It is apparent from the development of community services in the U.K. and elsewhere that normative settings are selected in the overwhelming majority of cases. However, there are views that the small houses scattered in the community for all types of disabled people are not the answer for everyone. Sheltered villages are suggested as one of the many types of residences. Wing (1989) points to the dilemma that, using the term normalisation, literally suggests that normality must be imposed on people whose disability and preferences would be better suited to a lifestyle that most people would find abnormal. Mesibov (1976) pointed out the value of the normalisation principle as a stimulus for action but also emphasised a number of problems. The most important of these was the need for evaluation of the usefulness of the principle in providing good services for the whole range of people with learning disabilities. Wolfensberger and Glenn (1975) agreed that normalisation had not been tested in this way. The principle tends to be applied in a blanket fashion to the whole group of disabled people rather than to individuals. Services set up in such a way may miss the needs of a substantial proportion of people with special problems.

Tyne (1992) warns about the dangers in the wholesale adoption of normalisation as the new "technical fix where normalisation is adopted as if it were a technology or a professional tool, particular elements of the ideas are sometimes taken and extended to bizarre lengths. So people who it is reasonable to assume will always need substantial amounts of help in their daily lives are subjected to lengthy training as a pre-condition to community living - a process where they often experience repeated failure. Others are denied special help, which they need, on the grounds that it wouldn't be normal" (Tyne 1992, P 44).

O'Brien's (1987) formulation of the five service accomplishments has drawn on the implications of normalisation in terms of what services should try to achieve or accomplish for users:

- ensuring that service users are present in the community by supporting their actual physical presence in the same neighbourhoods, schools, workplaces, shops, recreation facilities and churches as ordinary citizens;
- ensuring that service users are supported in making choices about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do;
- developing the competence of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that people value;
- enhancing the respect afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, forms of dress and use of language promote the perception of people with disabilities as developing citizens; and
- ensuring that service users participate in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual's network of personal relationships to include an increasing number of people.

O'Brien's notions of service accomplishments are devoid of the sociological trappings of Wolfensberg's theory. They place major emphasis upon delineating the implications of normalisation in terms of the lifestyle or quality of life of

members of the devalued group and return individual choice to a central position in normalisation (Brown and Smith, 1992).

The big challenge is to plan , provide and evaluate services in such a way that these aspirations are met for people with learning disabilities. One approach has been an attempt to operationalise such concepts under the heading of 'Quality of Life'. This is examined further in the next chapter.

Summary

Since the early 1990s the needs of people with learning disabilities have received considerable attention. The setting up of institutions in the first half of the century was aimed not just at providing care but also with a focus on education and training. The reaction against institutions developed in the 50s and 60s when concerns were identified regarding the quality of care and environments. A number of influential policy documents were formulated in the 70s and early 80s making it clear that, for the majority of people, community settings were considered to be the most appropriate provision for people with learning disabilities. At the same time the influence of the normalisation movement led to the setting up of small residences in communities for people with learning disabilities as the placement of choice - despite reservations in some quarters regarding the feasibility and appropriateness of this model of care for all.

Over the last three decades the combined influence of these developments has resulted in marked changes in residential provision for people with learning disabilities in the U.K. and elsewhere. There has been a significant reduction in institutional provision and a corresponding increase in community based services. There is a need to evaluate these changes and their impact on the lives of people with learning disabilities.

CHAPTER 2

QUALITY OF LIFE - ITS DEFINITION AND MEASUREMENT

Introduction

Dossa (1989) points out that quality of life has become a foremost issue, especially in human services. It is a phenomenon which has existed as long as man has lived on earth. However, the definition, measurement and evaluation of quality of life is a recent phenomenon, closely linked with the development of human services. The 'quality dimension' has been placed firmly on the agenda for human services in the 1990s (Osborne, 1992).

It is commonly acknowledged that researchers and service providers are hard put to define, quantify and evaluate the notion of quality of life. Gersen (1976) claims that different scholars, and sometimes even the same scholar (at different times), have entertained incompatible assumptions.

Quality of life has a central position in the evaluation of services for people with disabilities due to the major role which support services play in contributing to or even determining individual lifestyles (Felce and Perry 1995a). This has resulted largely from national political imperatives, professional groups and philosophical movements such as the normalisation ideology. As discussed in the previous section the underlying assumption of the normalisation philosophy is that an individual's quality of life, particularly his or her sense of self worth and satisfaction, will increase as a function of the extent to which the social group of which he or she is a member values him or her. Evaluation from the standpoint of normalisation is concerned with the effects of service provision on the image and status of the individual (Donegan and Potts, 1988).

As Felce and Perry (1995a) point out, many indicators of service process and outcome have been developed to characterise the impact of services on the lives of people with learning disabilities, chronic psychiatric morbidity, physical disabilities or infirmity due to old age and to assess the effects of fundamental policy change. However operational definitions of quality of life are diverse in both the general field and in those applied to defined populations.

Considerable work in the area of definition and operationalisation of the quality of life concept has taken place within the fields of general social welfare (e.g. Andrews and Whitney, 1976; Campbell, Converse and Rodgers, 1976); mental health (e.g. Baker and Intagliata, 1982; Bigelow, McFarland and Olson, 1991); physical disabilities and rehabilitation (e.g. Parmenter 1988) and learning disabilities (e.g. Borthwick - Duffy 1990; Felce and Perry, 1995a; Schalock, 1990).

It is generally accepted that quality of life is a multidimensional concept and can be represented in a number of ways. Rescher (1972) has maintained that there are two domains contained within the quality of life, the artistic and the hedonic. The former is concerned with the welfare of an individual, whilst the latter is concerned with the personal well being. This distinction has also been made elsewhere. George and Bearton (1980) talk of life qualities including "the conditions of life and the experience of life" whilst Robertson (1985) uses the term "welfare" and "happiness".

In this context "welfare" refers to the needs of an individual within society. The model often referred to is that developed by Maslow (1970). He suggests that people have five levels of need to be satisfied moving in hierarchical order from physical security up to self-fulfilment. Hornquist (1989) has suggested that rather than being a hierarchy, human needs are better modelled as a spiral, where several can co-exist and can be addressed at the same time.

"Well being" refers to the personal experiences of life and is defined by George and Bearton (1980) as having three components - life satisfaction, self esteem and happiness. This definition has generally been accepted and used elsewhere (Davies and Challis, 1986).

Borthwick - Duffy (1990) presented three perspectives on quality of life defined in terms of life conditions, satisfaction and a combination of life conditions and

satisfaction. Felce and Perry (1995a) developed this model to include personal values. These models look at the assessment of quality of life from both objective (life conditions) and subjective (satisfaction with those life conditions) points of view. However, some authors assert that only the subjective dimensions are relevant (e.g. Taylor and Bogdon, 1990). Felce and Perry (1995a) emphasise the need to incorporate both subjective and objective measures of quality of life. Ignoring the subjective domain is compatible with the argument that no citizen has the right to satisfaction with life but only the right to life or reasonable life conditions. Ignoring the objective assessment of life conditions may not reflect societal division and stratification. Nor may it provide the level of safeguard for vulnerable people which is associated with a measure that is to be accepted as the criteria for the adequacy of social policy in general and as the design and level of service and support in particular.

More recently it has been suggested (Cummins, 1993, Felce and Perry, 1995a) that evaluation of quality of life should also include the relative importance the individual places on the various aspects considered. Individuals may differ in the relative weight given to objective and subjective aspects of the same issue. In so doing, the concern that only individuals can decide the trade-off between competing aspects of their own personal welfare is met.

Evaluation of Quality of Life

Theoretical approaches to quality of life research are varied. Some researchers see value in an attempt to objectify and quantify quality of life (Stark and Goldsbury, 1990), whereas others believe that quality of life remains, by its very nature, an individually unique and subjective concept that defies measurement and demands qualitative approaches (Edgerton, 1990). However, if we accept that quality of life is defined as an overall general well-being which comprises both subjective and objective evaluations of physical, material, social and emotional well-being, then a combination of approaches to gain knowledge

regarding quality of life seems appropriate (Bradley and Knoll, 1990; Schalock 1990).

Objective evaluation refers to the description of life conditions under which people live, such as health, environment, housing, education, income, friendship, leisure etc. (Schalock, 1990; Zantura and Goodhart, 1979). These social indicators are good for measuring the collective quality of community life. However, they are considered insufficient to measure an individual's perceived quality of life or for evaluating the outcome of services because they only reflect an outsider's judgement of quality as suggested by external factors.

Subjective evaluation refers to psychological indicators such as personal satisfaction with life conditions. These indicators are used in an attempt to quantify a person's quality of life by assessing subjective reactions to life experiences. Attempts to measure these subjective evaluations have focused on psychological well-being and personal satisfaction/happiness.

In the past decade or so quality of life has emerged as an important theme in planning and evaluating services for people with disabilities. Landesman in 1986 pointed out that "the new buzz words in mental retardation are quality of life and personal life satisfaction" (p 41). The measurement of quality of life has potential that was well defined in Landesman's (1986) editorial in 'Mental Retardation'. "Once we define quality of life and propose measurable standards .....service providers and families will be better able to pursue innovative programmes to achieve these outcomes; social scientists can focus on developing strategies to measure specific sensitive outcomes and administrators and policy makers can adopt more reasonable effective means for monitoring their programmes"

Quality of life and its measurement have become important concepts in services for people with learning disabilities (Goode, 1990). Some reasons for this are greater general social awareness about issues of quality, growing concern about

quality of life in community placements for people with learning disabilities; dissatisfaction with current approaches to monitoring and evaluating service outcomes and quality of service, wider acceptance of consumers' viewpoints in determining satisfaction with life and acceptance of quality of life as a concept guiding clinical decision making and social policy formation.

Quality of life measures specific to the area of learning disabilities are emerging as the role of deinstitutionalisation, community integration and mainstreaming call for an outcome indicator sensitive enough for the evaluation of the shift in provision of services.

Many researchers have concurred that quality of life for people with disabilities comprises the same factors as quality of life for people without disabilities (Blatt, 1987; Goode, 1990; Schalock 1990; Turnbull and Bruik, 1990).

In the area of learning disabilities evaluation of quality of life has been fundamental to many recent publications on how services should be delivered. In the 1970s and 80s quality of life evaluations frequently focused on three aspects:

- quality of the physical environment in which people live (e.g. King, Raynes and Tizard, 1971);
- quality of care people receive from staff who look after them (e.g. Hemming, Lavender and Pill, 1981);
- degree of integration into neighbourhood as measured by use of physical facilities (e.g. Butler and Bjanes, 1978).

Over recent years a number of areas concerned with quality of life have received attention in evaluation studies on services for people with learning disabilities (cf Emerson and Hatton, 1994; Hatton and Emerson, 1996). In particular, objective indicators such as individuals' skills and competencies, living environments and engagement in activities have received attention. However, the more subjective areas such as emotional well-being and personal satisfaction

with lifestyle, while well reported in the general literature on quality of life, appear to be relatively neglected in the area of learning disabilities.

The Concept of Social Validation in Quality of Life Research

In the context of 'quality of life' research there is concern that typical operational definitions of quality of life suffer from bias in that they are too personal to the researcher's own subjective views or that they are measured by other things such as quality of care and environments or community participation (e.g. Stanley and Roy, 1988). One approach taken by some researchers has involved the introduction of social validation as a means of validating the measures.

In 1978, Wolf formally introduced the issue of social validity to the field of applied behaviour analysis. Essentially, he noted how rarely the consumers of behaviour - analytic programmes had been questioned about their acceptance of a programme's procedures, goals and personnel. He warned from experience that non-acceptance could precede disastrous consumer rejection of the programme and he recommended careful future assessment of consumer satisfaction from that point of view (Wolf, 1978).

Social validity has been heralded by some as an important guide for the future of the field (e.g. Baer, Wolf and Risley, 1987) and denounced by others as a detraction from the scientific nature of research practice (e.g. Barratt, 1987). Despite these differences, social validity measures are becoming almost commonplace in the behavioural literature.

The purpose of social validity assessments is to evaluate the acceptability or viability of a programme or intervention. Most often, social validity assessment is accomplished by asking people, other than the programme panels or experimenters, to complete some type of questionnaire (Kazdin 1977; Wolf, 1978). The point of these assessments is to anticipate rejection of a programme

before that happens; therefore, the assessment should involve all relevant consumers of the programme such as direct consumers, indirect consumers (e.g. parents of a person with learning disabilities) and members of the community. This information should be used immediately, as well as in future planning, implementation and evaluation. Thus, social validity assessments are not meant to be, and indeed are not, primary dependent measures; logically, they can only supplement the objective measures of behaviour that are the primary dependent measures (Barratt, 1987; Dietz, 1978).

Schwartz and Baer (1991) point out that social validity assessment is ideally a two part process: first an accurate and representative sample of the consumer's opinion is collected; then that information is used to sustain satisfactory practices or effect changes in the programme to enhance its viability in the community.

Simply recognising the existence of different groups of consumers and their possible stakes in programme outcome shows that programme adoption or programme rejection can not be predicted safely from a restricted sample of only direct consumers.

Schwade (1979) identifies three problems with social validation:

a) competence - is the individual competent to assess his/her views on the matter in question?
b) motivation - are members of the local community acting in the best interests of the client?
c) inertia - as a result of lack of competence and/or motivation is there a tendency for the status quo to be maintained?

This questions the ability of local community members to make judgements about what another person might value. However, this method of social validation has advantages in that it reduces the effect of subjective bias on the part of researchers, by employing the community's definition of quality of life as a point of comparison.

Shwartz and Baer (1991) identify a case for making social validity assessments routine in programme evaluation, in the same way as measurement reliability assessment is in current research practices. They also argue for the expanded consumer participation approach - however including a broader spectrum of consumers in social validity assessment, the issue of differentially weighting feedback from various groups of consumers, especially when that feedback is conflicting must be addressed. The purpose of social validity assessments is to provide information to help ensure programme survival. Therefore, the information from consumers most directly related to programme viability should be given the most weight. The question of what group of consumers most directly effects programme viability is empirical; however the detail necessary to answer these questions is not yet available.

Social Validity is not aimed at evaluating programme effectiveness but programme acceptability and viability.

A range of approaches have been adopted to determine social validity in research relating to quality of life. These include:

- identification of consumer judges (sometimes called clients or experts) who should assess the social validity of goals, procedures and/or effects (e.g. National Development Group (NDG) Checklist of Standards, 1980);

- selection of rating scales to obtain consumer judgements about qualitative dimensions in quantitative terms. Common forms of rating scales include semantic differential (with extreme values anchoring each end) and Leikert - type items (with each point anchored by a particular descriptor) of either 5 or 7 points;

- preparation of instructions for consumer judges to minimise potential sources of experimental bias and measurement artefact;

- assessment of the validity and reliability of the scale. Challenges to validity may be countered with assertions of face validity. Similarly measures of test/re-test reliability for scores of the same rater may be obtained to suggest the reliability of the assessment instrument; and

- identification of information about the behaviours or targets for clients, implementers or consumers that suggest social validity.

Although behavioural analysts may disagree on how to construct social validity assessments, there is a consensus that the role of consumers in the assessment process must be increased if we are going to improve the quality and validity of these assessments (Schwartz and Baer, 1991).

In their study Kosleski and Sands (1992) point out that analysing the habits and lifestyles of the general public can assist us in achieving social validity in our services to persons with learning disabilities. It is easy to lose perspective on what might be considered to be quality of life without a yard stick that can provide a guide for service decisions.

SUMMARY

The definition and measurement of quality of life for people with learning disabilities has received considerable attention over recent years. Quality of life as a subject of inquiry is closely linked with the principle of integration and implementation of the normalisation principle. There is general agreement that the assessment of quality of life should involve both subjective and objective measures. Objective indicators have been employed in many studies while subjective ones have been incorporated in few. There is a need to address the social validity of quality of life assessment in the evaluation of services for people with learning disabilities.

CHAPTER 3

OUTCOME STUDIES IN DEINSTITUTIONALISATION RESEARCH

Introduction

Seager (1990) in a review of international literature over the 60's, 70's and 80's noted less than 30 studies made any serious attempt to investigate the nature of the lives led by people with learning disabilities in the community. Only 10 incorporated any attempt to ask these people what they thought.

Most studies followed up people resettled from institutions in 'behaviour' terms. Success or failure was determined by whether or not an individual was re-admitted to institutional care with the assumption that the outcome was 'good' if this did not occur. Some studies focused on identifying factors associated with successful or unsuccessful community placement (Heal, Sieglmann and Switzky, 1978; Jackson and Butler, 1963; McCarver and Craig, 1974; Windle, Stewart and Brown 1961). The occurrence of behaviour problems in the community was the best indicator of re-admission whereas client pre-discharge functional ability was not consistently related to successful community placement (Crawford, Aiello and Thompson, 1979).

Since the early 80's researchers have begun to address "quality of life" issues focusing on client outcome variables.

A number of studies have examined the effects on various behavioural and quality parameters when people move to community based living arrangements. An impressive array of outcomes have been examined such as behavioural status (e.g. Fleming and Stanfert-Kroese, 1990; Hemming, 1986; Larson and Lakin, 1989; Lowe and de Paiva, 1990; Mansell, 1995); parent attitudes before and after deinstitutionalisation (e.g. Larson and Lakin, 1989,); aspects of the environment (e.g. Beswick, 1992; Cullen et al, 1995; Connelly Boyle and Smith, 1992; Felce et al, 1985, Felce and Perry, 1997) and a myriad of quality of life measures encompassing indicators of social presence, client satisfaction, friendships, peer interaction, etc. (e.g. Cullen et al, 1995; de Kock et al, 1988; Dockrell et al, 1993; Flemming and Stenfert-Kroese, 1990).

Attempts have been made to identify particular variables contributing to outcomes for people moving from hospital settings to care in the community such as individual characteristics and environmental features including size of living unit, staff:resident ratio, management practices etc. With respect to individual characteristics earlier research (cf McCarver and Craig, 1974) found little relationship between community adjustment (usually meaning no re-admission to hospital) and characteristics such as age, level of ability and length of hospitalisation.

The studies reviewed here examine a number of key areas in relation to outcomes for people moving from institutional to community settings. These are:

- features of the environment;
- competence and personal growth;
- patterns of interaction;
- engagement in activity;
- community presence; and
- psychological well-being and user satisfaction.

Features of the Environment

In view of the limited ability of individual characteristics and competencies to predict community adjustment, one might suppose that environmental factors play a large role in the adjustment process.

The emphasis on quality of physical environment is evident in its inclusion in written standards (e.g. Accreditation Council for Facilities for the Mentally Retarded, 1971; National Development Group, 1980). An axiom in the normalisation ideology is that physical environments are vital for promoting certain types of behaviour and social interaction. While the provision of a physically enriched environment would appear to provide the opportunity for a greater level of meaningful activity and interaction (e.g. Felce et al, 1985), it

does not in itself appear to be sufficient to ensure greater client participation (e.g. Landesman-Dwyer, 1982), or community integration (e.g. Sinson, 1990).

In the search for residential alternatives to institutional living the issue of "optimal size" is debated frequently. Many plead for smaller facilities on the grounds that small units are more personalised, "normal" and desirable. In the context of normalisation ideology size of living unit is an important variable.

Both facility size (e.g. King, Raynes and Tizard, 1971; McCormack, Balla and Zigler, 1975) and the size of the living unit independent of facility size (e.g. Harris, Veit and Allen, 1974) have been associated with a lower quality of care and with institution rather than resident orientated management practices. However, Butler and Bjaanes, (1978) found small community units to vary in quality - some replicating the worst aspects of large, total institutions. They found that very small facilities showed a less positive treatment environment than large facilities and speculated that small homes may hinder autonomy because of over protective staff.

Rotegard, Hill and Bruiniks (1983) found resident activity and autonomy to be higher in facilities with 5 to 8 residents than in those with 1 to 4 residents. Landesman-Dwyer, Stein and Sackett, (1988) found that social interaction occurred more frequently in larger group homes than in smaller ones. Other studies have found increases in the frequency and quality of interaction in small units as opposed to large units or institutions (e.g. Hemming, Lavender and Pill, 1981; Felce and deKock, 1989). A recent study, Felce and Perry (1997) employing PASS 3 evaluation (Wolfenberger and Glenn 1975) found smaller residences (1 to 3 residents) serving more able clients conformed more to normalisation ratings. It is difficult to draw any firm conclusion from these studies as resident characteristics have not always been controlled for adequately. Also staffing patterns will vary as a function of facility size and may along with other compounding variables, foster fake conclusions about the effects of size per se.

A number of studies draw attention to the error of assuming that increasing staff numbers leads invariably to higher quality care and interactions (e.g. Duker et al, 1989; Felce, 1988; Felce and Perry, 1994; Landesman, 1987; Moores and Grant, 1976).

These authors report that above a minimal level, staff/client ratios are unrelated to quality of outcome and there are diminishing returns from increasing staff numbers.

The exact relationship between environmental variables such as numbers of staff available and the physical setting in which they work with clients has shown to be complex (e.g. Felce et al, 1986).

Other areas such as management style have also been explored. Tjosvold and Tjosvold, (1983) note that collaborative management offers opportunity for residents to learn. Collaboration offers opportunities for high quality decisions, commitment to these decisions and improved self development and social competence of residents and staff members. They point out that it is not size of residences or quality of inputs, but how residents and staff members use their resources and, more broadly, how they relate to each other that affects residents.

Competence and Personal Growth

Increasing the competence, abilities and skills of people with learning disabilities and encouraging them to 'maximise their potential' provided one of the most important rationales during the early stages of the replacement of hospitals for people with learning disabilities with smaller community based forms of residential care. Emerson and Hatton (1994) point out that early evaluation research reflected the ethos with the 'success' of deinstitutionalisation being almost solely defined in terms of the rate with which users developed new skills. This area continues to be emphasised in research. There is no evidence that the

provision of community facilities alone will develop positive social functioning (Butler and Bjaanes, 1978; Edgerton, 1975; Lowe and de Paiva, 1990; McCarver and Craig, 1974).

The interest and importance placed on skill development is evidenced by its early inclusion in policy documents (e.g. Peters' Report 1979) and the emphasis given to this area in research studies. All studies reviewed primarily use questionnaires and rating scales completed by care staff (cf Emerson and Hatton, 1994; Hatton and Emerson, 1996). Virtually no attention has been given to assessing personal competence from service users themselves.

Adaptive Behaviour

Changes in adaptive behaviour are probably the most frequently used outcome measures of the effects of deinstitutionalisation (Emerson, 1985) and a variety of assessments have been used for this purpose. The most well known and widely used is the Adaptive Behaviour Scale (Nihira et al, 1974). Most adaptive behaviour scales or checklists cover all or some of the behaviour domains of self care, domestic activity, language development, social skills and recreational skills as assessed by care staff. Studies reported in Britain and the USA have revealed varying degrees of change in the area of adaptive behaviour with some showing an increase in personal competence associated with the move to smaller community settings (Connelly et al, 1992; Emerson et al, 1993; Knapp et al, 1992; Larson and Lakin, 1989) and a number reporting no change across the different service models (e.g. Beswick, 1992; Cullen, et al, 1995; Lowe and De Paiva, 1990). There is some evidence that improvements are most marked for residents who are least able (e.g. Felce and Perry, 1994, 1996; Lynch, Kellow and Willson1998; Shah and Holmes, 1987;).

Few studies have been longitudinal in design so findings relating to the maintenance of skills over a period of time are sparse. There is some evidence that initial gains are lost over time (Hemmng, Lavender and Pill, 1981) and,

where increases have taken place, these have often occurred immediately after community placement and plateaued thereafter (e.g. Hemming, 1986; Lowe de Pawa and Felce, 1993). Studies that employed 'control groups' provide information on adaptive behaviour for people remaining in hospital. Some report a decrease in adaptive skills over time (e.g. Beswick, 1992) while other studies have found increases in adaptive behaviour for hospital based residents over time (Hemming, Lavender and Pill, 1981).

Major findings from a number of the deinstitutionalisation studies reviewed indicate that changes are not entirely consistent from one study to the next. There was no behavioural domain which all investigators found the same change taking place. The diversity of results is not surprising, given the difference amongst the studies in numbers of subjects, the functional level of the subjects, the varying environments they were transferred from and moved into, and the different length of time within which they were followed up. Types of behaviour that improved in most of the studies were particularly language development, domestic activity and socialisation.

It has been contended (Emerson and Hatton, 1994; Kleinberg and Galligan, 1983) that improvement in functioning represents a manifestation of behaviour already in the clients' repertoire rather than new learning. The new environment provides the opportunity for the manifestation of those skills, not only in the sense of permitting but also in providing social reinforcement. The environment seems to have little effect, however, on certain areas of adaptive behaviour. Systematic training and education will be required for client improvement in these area.

Emerson and Hatton (1994) identify a number of problems in the interpretation of results in this area, such as:

- lack of knowledge concerning the interater reliability of the scales
- differing expectation of staff in 'institution' and community residences which may bias the responses of staff to questions regarding the abilities of

service users

- the problem in separating out increase in competence of service users from enhanced opportunities to display these competencies.

Maladaptive Behaviour

Emerson and Hatton, (1994) point out "one parallel aspect of the growth in the general competence of service users is the extent to which they show less evidence of 'challenging behaviours'. These are culturally unusual or unacceptable behaviours which are likely to lead to the person being excluded from or denied access to ordinary community settings".

Government policy, though favouring the development of community based services as alternatives to institutional care since the scandals of the 1960's and 1970's, has remained equivocal about the future role of institutions for people with multiple disabilities or with behaviour problems (Department of Health and Social Security, 1984; Department of Health, 1989). Recent government guidance (Department of Health, 1993) identifies the improvement of community services to meet the needs of people's problem behaviour as a major goal and accepts the use of institution only as a stopgap while this is being achieved.

There is evidence, as in American studies, that people with problem behaviours are less likely to be offered community services until the end of the deinstitutionalisation process (Wing, 1989). These people are also more likely to be reinstitutionalised (Intagliata and Willer, 1982; Pagel and Whitling, 1978) and, according to Mansell (1994), there is some evidence that English community services, where they are set up with emphasis on the normalisation ideology, rather than how to realise this in practice, may have particular problems serving people with problem behaviour. Maladaptive "problem behaviour" has been used as an indicator in evaluative studies from the 60's, when researchers examined re-admission rates and found that these were related to the presence of significant maladaptive behaviour.

The majority of studies evaluating changes in challenging behaviour do so by use of standardised rating scales which elicit information from care staff e.g. Adaptive Behaviour Scale (Nihira et al, 1974) and Disability Assessment Schedule (Holmes, Shah and Wing, 1982). A smaller number of studies reviewed by Emerson and Hatton, (1994) employ a method of direct observation to record amount of time users exhibited challenging behaviours (e.g. Emerson et al, 1993). Studies have found mixed evidence to support the view that moving to the community is associated with less or no change in the prevalence of maladaptive behaviours (e.g. Borthwick and Miller, 1981; Emerson et al, 1992; Evans et al, 1985;. Knapp et al, 1992; Mansell and Beasley, 1993).

As with adaptive behaviour - changes vary across studies in relation to 'reported' challenging behaviour. Different measuring approaches seem to yield different results. They suggest that, in part, the discrepancies between the approaches to measurement may reflect differential sensitivity to change among particular forms of challenging behaviour.

Patterns of Interaction

The area of social interaction has been subject of extensive research since Mead in 1934 introduced the symbolic interaction theory, which suggests children learn behaviours as a result of interaction with significant others. The importance of 'interaction' has been stressed since the early 1990's by researchers and educators and its relationship to development and well-being from birth of old age. The first systematic observation of interaction was in the area of mother and infant interaction. The extensive literature in the area of mother and child interaction has pointed to a number of issues such as relationship to cognitive functioning of the child (e.g. Dunst, 1978; Elardo, Bradley and Caldwell 1975) and the impact on the social development of the child of turn taking and reciprocating (e.g. Newson, 1979).

The work with 'normal' children has been extended to look at interaction patterns between mothers and other carers and children with learning disabilities. Compared to mothers of non-disabled children, mothers of learning disabled children are more dominant conversational partners and they use more language that is directive or controlling of the child's behaviour and less that is responsive to child initiated communication and actions (e.g. Buium, Rynders and Turnure, 1974; Cunningham et al 1981; Mahoney and Robenalt, 1986). The more dominant, directive and less responsive communicative style of mothers of children with learning disabilities seems to be a reaction to the passivity and communicative unresponsiveness of their children. This style appears to be a means of prodding children into more active communication. However, several investigators have speculated that a dominant, directive style may impede the communication development of non-handicapped children (e.g. Hoff-Ginsberg and Shatz, 1982).

During the 1980's and 1990's the interest in patterns of interaction has extended from the extensive work done on parent-child interaction studies to teacher-child studies in classroom settings and studies in institutional settings.

Similar findings in relation to interaction style of teachers with severely handicapped children have demonstrated lack of turn taking, high directive verbal output from teachers, few child initiated interactions and limited positive contact from adults (e.g. Beveridge and Berry, 1977; Bryan and Wheeler, 1976; Ware, 1987). Teacher behaviour with handicapped children has been found to vary dependent on ability level of children (e.g. Hackney, 1984; Ware, 1987). Some positive effect following staff training was noted by McBrien and Weightman, (1980) on both quantity and quality of interaction between staff and children.

Studies in institutional settings during the 1970's focused on the behaviour of institutionalised handicapped children and of the staff who supervised their daily

activities, often employing direct observational methods (e.g. Oswin 1978; Warren and Monday, 1971; Wright, Abbas and Meredith, 1974). These studies focused on the interaction patterns between profoundly and severely handicapped children and staff. The results of these studies are remarkably consistent in that very little interaction occurs at all and the quality of interactions that do occur are considerably poor.

Staff Contact

A good deal of work on interactions between staff and people with learning disabilities consists of observational studies in hospitals or other residential settings and have grown out of earlier work with psychiatric or acutely ill hospital patients. As early as 1953, Behymer stressed the importance of observing interaction patterns of nurses and attendants (Behymer, 1953).

It is widely known that the interaction patterns in institutional settings for people with learning disabilities are problematic in that they occur very rarely (e.g. Cullen et al, 1983; Felce et al, 1985, 1986 and Warren and Monday, 1971) and the quality of the actual interaction when they do occur is poor. Many studies in service settings in the 1970's and early 1980's have shown a virtual absence of interaction between staff and residents with a learning disability (e.g. Landesman-Dwyer, Sacket and Kleinman, 1980; Repp and Barton, 1980; Wright, Abbas and Meredith, 1974). This has also been shown in other areas such as elderly (e.g. McClannahan and Risley, 1975) and psychiatric care (e.g. Sanson-Fisher et al, 1979).

Studies which have examined the effects of environmental factors on the natural state of staff interaction with people with a learning disability have found:

- that increasing staff/client ratio by adding staff does not increase staff initiated contacts (Dalgleish and Matthews, 1980; Felce and Repp, 1992; Felce and Perry,1995a; Harris et al, Veit and Allen 1974; Landesman-Dwyer, 1981) and

may actually decrease the number omitted by each staff member (e.g. Mansellet al, 1982). Instead, more staff-client interactions may occur when there are less staff present;

- that clients with low rates of maladaptive responding and high rates of adaptive responding received more attention (Duker et al 1989; Grant and Moores, 1977), and that staff tend to interact with each other rather than with clients when more of their peers are available (Felce, Kushlick and Smith 1983; Moores and Grant, 1976);
- that some residents may experience restricted interaction, superficial or inappropriate interaction from staff as a consequence of their potential for destructive or aggressive outbursts (Grant and Moores, 1977) or simply because their physical appearance may be aversive or non-reinforcing for others. A review by Repp et al, (1987) indicates that staff interactions are not evenly distributed amongst residents, but may tend to occur more with a small number of people, especially those who are seen to be more attractive, intelligent and participative or less disruptive.

Tizard et al (1972) put forward the hypotheses that certain speech types, defined as "informative" are better for resident language development than others - such as "controlling speech function". Pratt, Bumstead and Raynes, (1976) found that more severely retarded adults living in a large residential institution were addressed less often in an informative manner by staff. Other studies have confirmed this variation in interaction leading to the assumption that the development level of the learner would seem to affect not only the form but also the function of the total speech sample directed to him or her by adults. Staff interaction with people with learning disabilities has consisted of few interactions deemed to be assisting in nature. More often staff were found to interact in a neutral way with residents (e.g. Felce and Perry, 1995a).

In their review of 46 studies (between 1980 and 1993) examining the effects of the move from hospital to community settings on the lives of people with learning disabilities in the U.K., Emerson and Hatton, (1994) identified 26

studies which examined the extent and nature of contact received by users from care staff. Most studies employed some form of direct observation (e.g. Beail, 1985; Dalgleish and Matthews, 1980; Durward and Whatmore, 1976; Emerson et al, 1992; Felce et al, 1986; Orlowska et al, McGill and Mansell1991). The majority of these studies focused their observations on the activities of service users and consequently only observed those aspects of staff behaviour which involved active contact with users.

Emerson and Hatton (1994) compared results across as well as within studies. While overall levels of staff contact were higher in staffed houses (14.8%) than either hostels (9.3%) or hospitals (4.2%) significant variation occurred within each type of service. Thus, for example, the amount of time users received contact from staff ranged from 3 - 16% in hospitals, 2 -17% in hostels and 5 - 31% in community based staffed houses. While the small number of studies evaluating staff contact in hostels makes the assessment of the statistical significance of differences across all types of services impossible, a comparison of hospitals with staffed houses reveals that users in staffed houses received significantly more staff contact than users in hospitals.

Peer Interaction

Although attention has been primarily focused on interaction between staff members and residents, relationships among residents can effect their well-being and their learning (Tjoswold and Tjoswold, 1983). Poor interaction is a greatly under-utilised resource to facilitate residents' development. Tjosvold and Tjosvold (1983) argue that "residents" are likely to learn important social skills and co-operation through interacting with each other. Social interaction and how people relate to their peers greatly effects the development and learning of learning disabled persons.

Few studies have reported findings on 'peer' interaction in settings for people with learning disabilities. While some positive changes have been noted in the

area of staff interaction for people moving from hospital to community residences, little change has been found in 'resident' interaction across settings for people with severe and profound disabilities, (e.g. Felce , De Kock and Repp, 1989; Mansell, 1994).

Engagement

Studies of people living in institutions have typically recorded low levels of engagement for residents in psychiatric settings (e.g. Sanson-Fisher et al, 1979, Pool and Dunn, 1989) elderly settings (e.g. Bowie and Mountain, 1991; Godlove, Richard and Rodewell, 1982; McClannahan and Risley, 1975) and settings for people with learning disabilities (e.g. Cullen et al, 1983; Hemming, Lavender and Pill, 1981; Thomas et al, 1986). For some groups low levels of engagement in activity was found across settings such as day centres, residential units, hospital wards (e.g. Godlove et al, 1982). A number of studies exploring the influence of staff-client ratio on engagement in purposeful activity have found little evidence to support the view that more staff allows for better 'engagement' (e.g. Raynes, Pratt and Roses, 1979).

The interest in this area is evident in that direct observation of the extent to which users are actively engaged has been the most frequently used measure of outcome in U.K. research over the past 14 years (e.g. cf Emerson and Hatton, 1994; Hatton and Emerson, 1996).

Emerson and Hatton (1994) state that the definition of engagement across studies has been used with sufficient consistency to allow for the comparison of results across as well as within studies. Of the studies reviewed (e.g. Auburn and Leach, 1989; Beail, 1988; Mansell and Beasley, 1990; Rawlings, 1988), levels of appropriate engagement were significantly higher in staffed homes (47.7%) than hostels (24.7%) or hospital wards (13.7%). There was significant variation with each type of service ranging from 2 - 23% in hospitals; 6 - 54% in hostels and 8 - 74% in staffed houses. Information relating to staffing ratios and ability

levels of clients were not included in most of the studies making it difficult to identify what variables may account for the observed variation within service models.

While the majority of comparative studies reviewed by Emerson and Hatton, (1994) indicated significantly increased levels of engagement in smaller community based environments, a minority of studies (25%) found no such change (e.g. Bratt and Johnson, 1988).

Community Presence

Community Integration

The presence of people with disabilities in community settings and their participation in community-based activities is often seen as the foundation for their true social integration.

No one definition of integration enjoys consensus and its definition has been elusive. Mark and Buckley, (1989) described integration "in its simplest and most elegant form as a degree of community presence and participation for persons with disabilities that is no different from that enjoyed by persons without a disability label" (p 320).

Four different components of integration have generally been considered (Mark and Buckley 1989). These are physical integration, social integration, relationships and social networks. **Physical Integration** is a necessary first step for other forms of integration - but mere physical presence may not necessarily lead to other forms of integration. **Social Integration** has been defined as "regular access to interactions with individuals without identified handicaps and regular use of normal community resources". (Will, 1984; p.2). Therefore for social integration to occur, interactions are a necessary condition. Competent social interactions elevate social perceptions of persons with disabilities (Gaylord - Ross and Peck, 1985).

A wide variety of measures have been used in measuring social integration which have focused upon social skills or discrete measures of social interaction (Nisbet, Zanella and Miller 1984; Yan et al,1990). "Relationships depend on social interactions that are ongoing and usually involve reciprocal participation in activities" (Mark and Buckley, 1989, p 320). Measures of relationships have focused on frequency and durability of contacts and type of interactions (Kennedy, Horner and Newton, 1989). Social networks generally refer to the people identified as socially important to a person. Mark and Buckley, (1989) refer to social networks as involving "repeated contact with a number of people who identify the relationships that exist with the group as "socially important" (p 320). Social contact patterns and social supports are directly related to social networks and are often conceptualised under the term "social life" (Kennedy, Horner and Newton, 1990).

Social networks generally have been assessed by measuring the size, structure, functions and adequacy of the network (Barrera, 1986). Self-fulfilment and satisfaction with one's quality of life have been highly associated with a stable social network (Haring, 1991). Storey (1993) points out that presently there is little empirical understanding of how social relationships and social networks for people with disabilities form and how they effect the quality of life of these persons.

Participating in Community Activity

In their review of British deinstitutionalisation studies since 1980, Emerson and Hatton (1994) found 20 of 46 separate studies included data on the extent service users participated in community activities.

Most commonly the studies assessed the use of community based facilities (e.g. shops, cinemas, banks etc.) either retrospectively through interviews with the staff (e.g. Dockrell et al, 1993) and/or service users (Jahoda Cathermole and Markova, 1990; Martin, 1982), prospectively using some sort of diary

completed by care staff (e.g. Bratt and Johnson, 1988; de Kock et al, 1985, 1988; Evans et al, 1985; Fleming and Stenfert-Kroeze, 1990) or the use of direct observational approaches (e.g. Joyce, Mansell and Gray, 1981). McConkey, Walsh and Connelly (1983) interviewed neighbours of service users living in staffed housing regarding the amount of contact they had with service users.

Participation is often used as an objective measure of quality of life. (Butler and Bjannes 1978). The presence of people with disabilities in community settings and their participation in community based activities is often seen as the foundation of their true social integration.

A number of researchers (Amado, 1988; Edgerton, 1975; Parameter, 1988; Seager, 1990) have observed that deinstitutionalisation has allowed persons with a learning disability to live in community settings but they are far from integrated into community life.

The impetus for increased community based residential placements was derived in part from the logical assumption that such placements naturally lead to increased participation in community activities and increased utilisation of community resources. An important aspect of community living concerns the contact made with family, friends and neighbours. Sigelman et al, (1981) found that people with learning disabilities produce a high level of acquiescence, a behaviour which is not conducive to the development of satisfactory relationships. Raploy and Firth, (1986) have outlined some of the barriers which people with learning disabilities may face in making relationships. They have difficulty in getting to places where people meet because of lack of money and transport. They may have difficulty in communication or have been deprived of opportunities to learn everyday social skills (Donegan and Potts, 1988). However, there is limited information available from patterns of social contact between persons with learning disability and typical members of local community. Research suggests that there is variability across people and the

type of setting where they reside (e.g. Kennedy, Hornew and Newton, 1989; 1990).

A number of studies in the U.K. which have examined the frequency of social contacts in community settings compared to hospitals have reported an increase in the frequency of social contacts in the community settings (e.g. Booth, Booth and Simons, 1990; de Kock et al, 1988; Lowe and de Paiva, 1991). However the frequency of contact with people who are not resident , staff or relatives remains very low (e.g. Cathermole et al, 1988; Fleming and Stenfert-Kroeze, 1990; Knapp et al, 1992).

For some people there was no reported change in the use of community facilities in smaller community settings as opposed to hospitals (e.g. Beswick, 1992; Knapp et al, 1992; Emerson et al, 1993) or initial changes were not maintained over time (e.g. Clare and Murphy, 1993).

While studies have adopted different approaches to the evaluation of community participation and reliability data has not always been quoted or reliability has found to be low (e.g. Joyce et al, 1989) - in general the research supports the view that 'being' in the community increases the opportunities for being 'part' of the community. Emerson and Hatton, (1994) point out, however, that improvements generally occur from a very low baseline in hospital settings and that community contact in community based services may still be relatively superficial and infrequent.

User Satisfaction

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Advocates of deinstitutionalisation have implicitly assumed that the happiness of individuals with learning disabilities is inevitable when they are transferred from an institution to community residential and day services programmes.

While it has been long recognised that people should be involved in assessing their 'quality of life' many researchers excluded the view of people with a learning disability on the basis that they are least able to conceptualise and articulate and therefore focus on the more objective measures. In 1981 Landesman - Dwyer in an address to the Residents Committee on Mental Retardation in the U.S. stated "As much as possible assessment of quality life should be from the viewpoint of individual clients ..... rather than our own perspective". A number of researchers have shown that with care it is now practical to involve these individuals in research and service evaluation (e.g. Cullen et al 1995; Flynn, 1989, Lowe et al, 1986; McKenzie, 1990; Walker, Ryan and Walker, 1993). To date methods of seeking information from service users have been obtained by structured or semi-structured interviews (e.g. Flynn, 1989). The use of visual aids to assist in eliciting information has been employed in some studies. The fact that persons with learning disabilities continue to have unmet needs, in spite of living in a homely environment with access to community facilities (Stanley and Roy, 1988), underlines the point that it is important to include subjective indicators in the assessment of quality of life.

Summary

Over the past 20 years a number of studies have been carried out to examine the effects of deinstitutionalisation on the quality of life for people with learning disabilities. There is considerable variation in outcomes reported from one study to the next. However, some general conclusions can be drawn:

- there is some relationship between the size and management organisation of living units and quality of life of residents - although many other factors seem to be involved;
- variable results have been reported regarding improvements in individuals' skills levels and competencies as rated by staff. No studies have sought individuals' own views about this;
- some improvements have been found with regard to the rate and quality of

interactions received from staff - although very little has been reported on the nature of interaction between residents;

- some improvements have also been found for resident engagement in activity;
- there is insufficient information available on the relationship between resident behaviour and staff behaviour in the area of learning disabilities (although a considerable amount of research has been carried out on other groups, e.g. parent - child; teacher - child);
- people may be physically integrated in community settings but are a long way from being socially integrated; and
- few studies have addressed the subjective dimensions of quality of life such as personal satisfaction and psychological well-being.

CHAPTER 4

RESEARCH ISSUES AND METHODOLOGICAL CONSIDERATIONS

The historical development of services for people with learning disabilities points to a range of issues that have impacted on where, when, what and how services are provided. While early empirical studies have influenced, to some extent, both the setting up of institutions and the deinstitutionalisation movement, many other issues have probably had a stronger bearing. Political, philosophical, cultural, social and not least economical factors have all contributed to varying extents to the changes in service provision for people with learning disabilities. There is however a general consensus that people are generally better off in terms of their environment and lifestyle when they move although gains may be both modest and variable.

It appears that the literature has not been sufficiently robust to allow for unequivocal and widespread support for deinstitutionalisation as evident in calls from professionals (cf Lamb, 1993). Some resistance has been a reflection of a wider concern, that deinstitutionalisation is not always a policy which is informed by empirical data but is sometimes more influenced by fashion and financial exigencies (Cullen, 1995; Scull, 1990).

Emerson (1988) argued cogently that we should be moving from wondering whether deinstitutionalisation does or does not work to asking questions about actions which are of relevance to service users. One empirical question that requires to be addressed is what specific settings are most valuable for what kind of people. A key issue is the relationship between user characteristics, the structural and procedural characteristics of settings and performance across a wide range of outcomes. In this context a number of research issues are considered.

1) Many measures of quality of life have been employed in evaluative studies. There are a range of views as to what does or does not contribute to quality of life for people with learning disabilities and whether it is the same or different from other people. The need to

address the social validity of quality of life assessment is an important area for research to address.

2) There is general consensus that quality of life requires to address both objective and subjective perspectives. As has been pointed out earlier, there are some difficulties in accessing the subjective views of people with learning disabilities and only a few studies have made any effort to address this. In particular it has been difficult to evaluate psychological status and mood states. There is some evidence that people with mild learning disabilities can make valid and reliable responses on self report evaluations (e.g. Prout and Schaffer, 1985) although this is an area rarely examined in evaluation studies of different service models.

Clearly objective measures are important but on their own may miss out on an important dimension. Horner and Heal (1993) point out that a comprehensive measure of an individual's quality of life should include a measure of social indicators in the environment, a measure of psychological indicators of happiness and satisfaction and a measure of the fit between the person and his or her environment. While many measures exist for use with the general population there is a lack of research on how best to 'tap' into these areas for people with learning disabilities.

3) It is apparent that while people with learning disabilities are living in community settings there is a lack of research evidence in relation to what skills and behaviours are necessary to achieve community presence and to enable people to participate in the life of the community (cf O'Brien, 1987). Many people have assumed that placement in the community is sufficient to achieve successful integration and participation.

4) The very nature of services for people with learning disabilities means that care staff play a crucial role in the achievement of a higher quality of life for the people they care for. The relationship between staff and resident behaviours is one requiring considerable attention in further research.

5) While a number of studies have addressed some aspects of quality of life for people with learning disabilities moving from hospital to community settings (cf Emerson and Hatton, 1994; Hatton and Emerson, 1994) many have quoted relatively small numbers (under 12) of people and few have looked at people over a prolonged period of time This raises a question in relation to generalisability of findings. In a review of 46 separate studies carried out in the U.K. since 1980 (cf Emerson and Hatton, 1996) on some aspect of the characteristics or quality of residential services for people with learning disabilities, only four studies included 50 or more individuals from the same setting (e.g. Felce, 1994; Flynn, 1989; Hewson and Walker, 1992 and Knapp et al, 1992). Of these only one (Knapp et al, 1992) looked at the same people in two settings (hospital and community) and at a comparison group (not a control group) of people remaining in hospital.

6) A related issue is that of maintenance. Do improvements continue over time, or do people stay the same, or do they get worse? The vast majority of studies have examined people at one point in time or have conducted a pre - post move comparison. There is evidence from a few studies that gains made following a move from hospital to community are variable and not always consolidated.

7) With the emphasis on the rundown of hospitals and eventual closures, little attention in recent years has been given to those people who are still in hospital and are likely to be for some years to come. There are several

questions to address in relation to this such as whether their quality of life is getting worse, improving or staying the same.

As deinstitutionalised programmes continue, it is necessary, on an on-going basis, for data to be gathered over a period of time which will give a more accurate and detailed picture of what happens to people when they leave the institutions and also for those who still remain. There is a need to identify areas which represent significant challenges to community based residential services. This involves widening the range of measures used to ensure that quality of life in its multidimensional construct is assessed validly and by meaningfully involving service users and others. This leads to the identification of outcomes which have a real bearing on the agendas of policy makers and service users, as suggested by Emerson (1985). The research reported here was carried out as a contribution to this exercise.

Within the overall framework of the research on quality of life three separate but related studies were undertaken to address some of the major questions identified in the context of assessing quality of life for people with learning disabilities.

Study 1 was designed to assess the social validity of some aspects of quality of life in relation to people with and without learning disabilities.

Study 2 was designed to investigate the effects, over time, on a number of objective and subjective indicators of quality of life for:

(i) a sample of people with learning disabilities who left hospital to live in a range of community residences and

(ii) a sample of people with learning disabilities who remained in hospital.

Study 3 was designed to examine resident engagement and patterns of staff : resident interactions for:

(i) a sample of people with learning disabilities who left hospital to live in a range of community residences and

(ii) a sample of people with learning disabilities who remained in hospital.

As the research studies were conducted in naturalistic settings a quasi experimental design was adopted utilising a pre-matched control group and longitudinal repeated measures designs.

CHAPTER 5

STUDY 1

SOCIAL VALIDITY AN EXPLORATORY STUDY

I Establishing Social Validity - Community Sample

II Establishing Social Validity - Learning Disability Sample

Introduction

One of the major difficulties in the evaluation of services for people with learning disabilities is that some clients of the services are neither able to express their own views nor are they given the opportunity to identify desired outcomes for services they receive.

The goals for services and their measurement have been developed by and based primarily on 'expert opinion' (e.g. National Development Group, 1980; Wolfensberger and Glenn, 1975; Wolfensberger and Thomas,1983) without necessarily seeking the views of service users or others.

While these and a range of other measures have been widely used in the U.K. and U.S.A. (Felce and Perry, 1997; O'Brien and Tyne, 1981) to evaluate services and aspects of recipients' quality of life, some concerns have been expressed regarding their validity. For example, in relation to PASS (Wolfensberger and Glenn, 1975) Landesman - Dwyer (1981) pointed out that "such an instrument makes an apriori assumption about what is good for all individuals and accepting such instruments without validating the underlying assumption is a questionable practice" (p228). With regard to the National Development Group Checklist of Standards (NDG, 1980) Raynes (1988) noted that "no piloting of the standards had been undertaken, nor have they been validated. However it is almost all that has been developed in the United Kingdom in the way of a set of standards based on experience and views of 'experts' against which we can monitor the quality of care being provided to people with a learning disability" (p26). Recent work on defining a model for quality of life and its measurement (Felce and Perry, 1997) also points to the need to establish its social validity.

There is general consensus that the opinion of the consumers of programmes who are most likely to be the recipients of the programme should be sought. Consumers can also include indirect consumers such as parents of a person with a learning disability; members of the immediate community who interact with the direct and indirect consumers on a regular basis (e.g. neighbours of a group

home) or members of the extended community, which would include some people who probably do not know or interact with the direct and indirect consumers but who live in the same community (cf Schwartz and Baer, 1991).

The present study was concerned with establishing the social validity of standards set by the National Development Group in 1980 and to develop, from this, appropriate measures for assessing aspects of quality of life for people with learning disabilities.

In 1980 the National Development Group produced the checklist of standards which incorporated measures of the physical environment, opportunities for individual development and the provision of appropriate services. The standards were set by 'interested' experts based on what informal opinion believed to be the basic principles which services in their quality should reflect. A number of checklists and monitoring instruments were drawn on in the development of these standards (e.g. King, Raynes and Tizard, 1971; Raynes, Pratt and Roses, 1979).

In all there are 244 standards in the checklist covering four principles relating to:

- interdisciplinary assessment of individual needs and training to meet those needs
- the provision of services to enable people with learning disabilities to stay at home
- the provision of services which promote the development and independence of people with learning disabilities
- joint planning and policy making

The authors stated that the completion of the checklist would provide a range of detailed information on the basis of which the quality of a local service could be evaluated and plans made as necessary to improve it.

It was outwith the scope of this study to attempt to validate all of the standards relating to residential services. The standards relating to the promotion of development and independence were considered most appropriate in the context of deinstitutionalisation. In particular standards relating to the following areas were selected:

- access to, and use of, facilities
- relationships with staff, family and friends
- patterns of daily life
- promoting client independence
- planning clients' training
- aspects of the physical environment

These issues relate to some of the five major service accomplishments identified by O'Brien and Tyne, (1981) with emphasis on physical presence in community settings; providing opportunities to enable clients to make choices and enhancing respect afforded to service users.

The specific aims of the present study were therefore -

(i) to assess the relative importance of a number of the National Development Group's recommended standards for service provision against the views of the "extended wider community" (cf Schwartz and Baer, 1991) which would include people who possibly did not know or interact with people with a learning disability;

(ii) to assess the relative importance of the same standards as rated by direct consumers i.e. people with a learning disability; and following on from (i) and (ii).

(iii) to develop an appropriate measure reflecting some aspects of quality of life for people with learning disabilities.

I Establishing Social Validity - Community Sample

In assessing social validity Schwartz and Baer, (1991) identify three questions:

What to ask your audience?
Who constitutes your audience?
How to assess your 'audience' reliability?

In relation to the first question the main issue of interest in the present study was to identify the importance and relevance of the specific standards or goals to desired lifestyle.

A questionnaire was developed consisting of 96 items covering the areas identified above from a selection of the NDG standards and is presented in full in Appendix 1. Questions were phrased in a way that would assess their relative importance to the respondent and examples are shown in Table 1. As a number of the standards related specifically to learning disability services some of the questions asked for views on their relative importance for people with learning disabilities. The questionnaire was therefore divided into two sections.

Section 1 consisted of 74 questions concerned with the importance of a number of aspects of daily life and features of the physical environment to the respondent.

Section 2 consisted of 22 questions asking for the opinion of the respondent on a number of aspects of services for people with a learning disability such as contact with staff and patterns of daily life.

Items were rated on a 5 point Likert Scale from not important to extremely important. This allowed the relevance of items in the questionnaire to be assessed. The majority of social validation research reviewed by Storey and

Horner (1991) used either a 5 or 7 point Likert type scale which allow for a wide variation of consumer responses.

Table 1

Social Validity Study - Community Sample
Example of questions based on the National Development Group Checklist of Standards

National Development Group Standards		Social Validity Questionnaire Community Group	
Facilities (60)	The need for a residential/day facility to be close to community facilities. For a facility to have 12 adults or less in a group	Section 1	How important is it: ◊ that local shops/public transport are within easy access? ◊ to live permanently with less than 12 others
Relationships (136)	Are families and friends allowed and encouraged to visit the unit at any convenient time to see a client?		◊ for visitors to be able to call at any time?
(135)	To what extent is the client allowed and encouraged to make regular visits home or visit friends or relations?		◊ to regularly visit families and friends?
Patterns of Daily Life	To what extent is the client given flexibility in choosing when to get up and when to go to bed?		◊ to choose when to put your light out at night? ◊ to be able to stay up later than 10.00 pm?
Promoting Independence (116)	Is each client given the opportunity to choose clothes from a range? Wear the clothes he/she wants?		◊ to be able to choose which clothes to wear?
Physical Environment (48)	When choosing furnishings, decoration etc. to what extent is the client consulted?		◊ to be consulted about your own home decor? ◊ for the decor to be varied from room to room?
Planning Client Training (95)	To help the clients' training , does the unit select goals for each client to achieve?	Section 2	for a mentally handicapped person to have a written individual programme plan?

Procedure

Prior to circulating the questionnaire widely a pilot study was conducted. This was administered to 20 individuals not involved in the study who were asked to note any unclear or ambiguous questions. Such items were reworded and clarified in the final version of the questionnaire. The results of the pilot study were not used in the final analysis.

Over a month individuals were approached in the street, bus station and a local health centre and asked to complete the questionnaire. Questionnaires were also distributed to the local University and circulated to staff and acquaintances. It is recognised that the group therefore included a range of 'consumers' with varying degrees of knowledge and experience of people with a learning disability. The nature of the project was briefly explained to them and the researcher was on hand to discuss any specific queries. Individuals were assured of the confidentiality of their replies. In all cases individuals completed the survey voluntarily, receiving no compensation for their participation.

Subjects

Participants in the study were 200 members of the general public. The following groups were targeted in order to obtain as random a group as possible:

- individuals waiting at a bus station
- shoppers at a large shopping centre
- attendees at a local health centre
- university students
- nursing and medical staff
- friends, relatives and neighbours of the author and her colleagues

While over 300 questionnaires were circulated, a total of 200 individuals from Edinburgh and Fife completed the questionnaire. Information pertaining to subjects' characteristics such as age, gender and degree of contact with people with a learning disability are shown in Table 2.

Table 2

Social Validity Study Community Sample (N=200)
Age, Gender and Degree of Contact with People with a Learning Disability

		Number	%
Gender	Male	96	48
	Female	104	52
Age Range	18-20	22	11
	21-30	84	42
	31-40	49	24
	41-50	28	14
	Over 50	17	9
Mean	32		
Median	27		
Contact with people with a learning disability	Virtually none	106	53
	A little	59	29
	A lot	35	18

Participants' ages ranged from 18 to 66 with a mean age of 32 years (median 27). Over half the sample had no contact with people with learning disabilities. The sample was considered to include appropriate representation from the immediate and extended community as described by Schwartz and Baer (1991).

Results

Reliability

While it was not possible to obtain data on a test-retest reliability from a cross section of the sample, because they were unknown to the author, 22 different individuals (just over 10%) agreed to complete the questionnaire on two occasions a week apart. Questionnaires were coded to allow the 'reliability' sample to be identified.

Test-retest reliability was calculated as a percentage index: (cf Baer, 1977)

$$\text{percentage agreement} = \frac{\text{no. of agreements}}{\text{no. of agreements + disagreements}} \times 100$$

The absolute percentage agreement levels and agreement within one scaled point for each question is shown in Appendix 2. While only 6 of the 96 questions have absolute agreement levels of 80% or above, all but one question 'How

important is it that birthdays are celebrated'? have agreement levels of 80% and above when agreement within one scaled point is taken into account. The level was considered acceptable for the purpose of the present study.

Details relating to the individual rating of importance and median scores for each question are contained in Appendix 3.

The scores attributed to each item were summed. The number and percentage of responses in each category are shown in Table 3 below. The data are skewed with most of the responses (73%) falling into the 'very' or 'extremely important' rating.

Table 3

Social Validity Study - Community Sample
Overall Number and Percentage of Responses in Each Category

	Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
	1	2	3	4	5
Number	894	1009	3147	5260	8890
%	4.6	5.2	16	27	46

95 of the 96 questions were rated by over 50% of the respondents as being at least moderately important while 84 of the 96 questions were rated as being at least moderately important by over 80% of the respondents.
Table 4 below gives a breakdown of the number and percentage of questions agreed upon as being moderately, very or extremely important by over 50% to over 90% of the local community sample.

Table 4

Social Validity Study - Community Sample
Number and Percentage of Questions Agreed as being Moderately to Extremely Important

	Over 50%		Over 60%		Over 70%		Over 80%		Over 90%	
	No	%	No	%	No	%	No	%	No	%
At least moderately	95	99	94	98	91	95	84	88	56	58
Very to extremely	83	86	70	73	61	41	41	43	25	26

Only one question was considered unimportant by the majority of respondents which was the question relating to having your own toys.

While it would have been desirable to weight each question and develop a scoring system whereby items were scored according to their relative importance, this was outwith the limitations of the study. It is expected that some items would be considered of greater importance than others and this is discussed further below.

II Establishing Social Validity - Learning Disability Group

Having identified the relative importance of items to the extended community, a separate study (McKenzie, 1990) was conducted to assess the views of people with learning disabilities. This allowed for an assessment of 'direct consumers' views as defined by Schwartz and Baer (1991).

Subjects

A total of 56 people with learning disabilities living in a range of settings were included in the study.

Four separate groups were identified:

1 Residents of a local hospital for people with learning disabilities (N=17)
2 Previous residents of the hospital now living in the community (N=14)
3 Lifelong community residents (N=11)
4 Residents of the State Hospital (N=14)

Data were collected from all four groups regarding gender, age, length of hospitalisation and degree of learning disability. Table 5 identifies characteristics of subjects by place of residence.

Table 5

Social Validity Study - Learning Disability Sample
Characteristics of Subjects by Place of Residence

	Local Hospital N=17		Previous Resident N=14		Community Residents N=11		State Hospital N=14	
Age (years) Mean and SD	42.9 (12.0)		43.1 (11.5)		35.0 (8.8)		32.9 (10.3)	
Length of Hospitalisation (years) Mean and SD	20.2 (8.9)		21.2 (10.8)		0		10.8 (8.6)	
Gender Male	12		9		6		10	
Female	5		5		5		4	
Diagnosis	N	%	N	%	N	%	N	%
Mild	12	71	11	79	8	73	11	79
Moderate	5	29	3	21	3	27	3	21

The subjects represented a sample of adults with learning disabilities from a variety of residential settings. The mean ages ranged from 33 years to 43 years with length of hospitalisation being shortest for the group from the state hospital.

As there was a requirement for subjects to be able to participate 'verbally' in the study, people with profound learning disabilities or serious communication difficulties were excluded. Most subjects were considered to be functioning within the mild category of learning disability as assessed by clinical opinion (ICD 10, WHO, 1992). Consent was sought from each participant with the involvement of a member of staff if appropriate.

Procedure

A modified form of the questionnaire carried out with the community group was used, the main difference being in the wording and a slight reduction in the number of questions from 94 to 87. This was as a result of combining some similar questions. This formed the basis of a semi structured interview, covering the importance of the various items to the subjects (a copy of the questionnaire is contained in Appendix 4).

Care was taken to develop a method of interviewing that would minimise the likelihood of obtaining inaccurate information and guidelines suggested by Flynn (1989) were followed.

Subjects' understanding of the concept of 'importance' was assessed by asking them to give a few examples of things that they cared a lot about and those were then redefined as being important to them. Individuals were then asked if each particular questionnaire item was important in a variety of ways e.g. 'would it matter if X ? Is it important to do/ have X ? Would you mind if X didn't happen? etc. An exploration was then made of the individual's response. If an individual indicated that an item was important or unimportant he/she would be asked to explain why. While each area in question was explored with subjects given as much time as was required for clarification and obtaining clear and audible responses, response recording was kept to a minimum by reducing answers to a 'yes', 'no' format.

The interviews took, on average, 40 minutes and all but 5 subjects were able to justify their opinions. The data for those 5 subjects were discarded.

Results

Reliability

Inter-rater agreement was assessed by testing 15 subjects (approximately 30%) within a two day period. Inter-rater agreement for the vast majority of questions (80/87) was 80% or above which is the level commonly accepted by researchers as indicative of a satisfactory level of inter-rater reliability (Harrop, Faulkes and Daniels 1989). Test-retest reliability was conducted on fifteen subjects one week apart and yielded a high level of agreement with 81/86 questions having levels of agreement of 80% or more.

Appendix 5 contains the detailed ratings.

The ratings of importance of the questionnaire items by the people with learning disabilities were consistent with those of the community group. The individual scores for each question can be seen in Appendix 6. Table 6 shows the number of questions agreed upon as being important by 50% to 90% of subjects. All but one question (to have toys) was rated by over 50% of the respondents as being important. Of the remaining 86 questions, 84/86 were rated by over 78% of the subjects as being important while 13 of the questions have 100% agreement on their importance.

Table 6

Percentage Agreement Between Subjects

%	over 50	over 60	over 70	over 80	over 90
Total No. of Questions	86	85	84	81	60

No significant differences were found for subjects on the basis of age and gender.

A chi square test was used to examine for significant differences in responses from subjects in each of the four residency groups. Seven questions were found which had significant differences in responses between the four groups.

Overall, however, the results from the community group and learning disability group supported the inclusion of the items developed from the NDG checklist of standards as valid measures of service evaluation on quality of life for people with learning disabilities.

The social validity of the items was obtained and these results informed the development of two measures, one to assess the living environment and management practices and the second to assess individuals' lifestyles. All items rated as moderately or very important by local community group were retained. The questionnaires are contained in Appendices 21 and 22.

Discussion

The present study set out to assess the social validity of a set of standards developed by the National Development Group against the opinions of the wider community and of people with learning disabilities. All of the items, except one, were considered at least moderately important by the community group and similarly considered important by the learning disability group.

The results from this study informed the development of two measures relating to aspects of quality of life for people with learning disabilities to be used in the evaluation of different service models described in Study 2 later in this thesis. The measures related to the assessment of the living units and of individual lifestyles. They are considered to have social validity to the extent that their content is based on items considered important by the local community and people with learning disabilities. This is in accordance with the principle of normalisation which affirms that valued and familiar methods should be used to provide each person with life conditions and opportunities which are as socially valued as those of the average citizen (Wolfensberger, 1972).

A number of methodological limitations to the present study are considered.

Firstly, selecting a truly random sample of the general population was difficult. Interpretations based on relatively small samples need to be viewed with some caution.

Secondly, while almost all items were rated as at least moderately important by the community group and as important by people with learning disabilities in a range of settings, there is a need to consider specific values and weightings for each item.

Thirdly, it is apparent that some items are considered more important to individuals with learning disabilities dependent on where they live. It is obvious that people living in the state hospital have different expectations and goals in the context of the specific culture. Modification of a measure may need to be undertaken to be sensitive to these differences.

Finally, a practical difficulty with this form of evaluation is that community 'norms' are essentially local in nature and hence may not 'travel' well or generalise to other areas. It would probably be necessary for evaluators to develop community norms in their own geographical area (cf Stanley and Roy, 1988).

Despite these methodological limitations, the present study was an attempt to take seriously the need to 'check out' the goals of service models with the users of that service and the community in which they live and to tap into the complex area of personal values. The findings from the present study contribute to the debate on objective quality of life research and go some way to removing the effect of subjective bias on the part of the researcher regarding a definition of quality of life.

Schwartz and Baer (1991) identify a case for making social validity assessment routine in programme evaluation as measurement reliability assessment is in current research practices. They also argue for the expanded consumer participation approach by including a broader spectrum of consumers in social validity assessment. The issue of differentially weighting feedback from various groups of consumers is relevant in order that information from consumers directly related to programme viability is given the most weight.

The present study has made a contribution to this area.

Further work will allow new service models to be evaluated against the community's own values and those of people with learning disabilities in a meaningful way.

CHAPTER 6

THE STUDY METHODOLOGY - STUDY 2

An evaluation of changes in some aspects of quality of life brought about by the relocation of people with a learning disability from hospital to community residential establishments.

The Experimental Hypothesis and Research Design

The overall experimental hypothesis of the study was that there would be improvements experienced on a number of important quality of life outcomes for people with learning disabilities who left hospital to live in the community relative to any (or no) changes experienced by people who remained in hospital.

The study was designed to examine the effects of relocation on a number of variables deemed to be indicators of quality of life for a sample of people moving from hospital to live in the community (i.e. "movers") and for a sample of people remaining in the hospital (i.e. "stayers). Outcome measures selected and described in detail later in this chapter, covered adaptive and maladaptive behaviour, community living skills, social skills, living environment, lifestyles and psychological well-being.

For both groups, repeated measurement over time of the specific variables provided a longitudinal focus to the hypothesis under study - utilising a repeated measures design across participants and a matched control group design.

Three specific hypotheses were under investigation for people moving from a hospital to a community setting:

- there would be an increase in their competence and personal growth;
- there would be a positive impact on their psychological well-being;
- there would be an increase in the quality of care provided.

For people remaining in hospital over the duration of the study there would be no change in the above.

The independent variable under investigation "in hospital" condition and "in community" condition allowed for an effective research study to take place within the natural environment setting.

As there is a dearth of longitudinal studies examining the impact of relocation on people with a learning disability who leave hospital and particularly on the impact on those who remain (c.f. Emerson and Hatton, 1994; Hatton and Emerson, 1996), the present study aimed to follow participants up over a 3 year period. The first assessment was referred to as the baseline assessment (T1) with subsequent assessments for each participant taking place at six monthly intervals - 6 months (T2), 12 months (T3), 18 months (T4), 24 months (T5) and 30 months (T6).

Background

While most people with learning disabilities already live in the community with parents, the focus of the present study was on those people still living in hospital. The study was carried out within the context of an agreement with Fife Health Board and Fife Regional Council Social Work Department, in 1987, to move a group of residents from Lynebank Hospital in Fife to a range of community residential settings. Lynebank Hospital is a purpose built building opened in 1969 with a bed complement, at the time of the study, of 320. Lynebank was one of the last new hospitals for people with a learning disability to be built in Scotland and was, at the time, considered a positive step forward in the provision of services. However, the plans and opening of the hospital predated, by only a few years, the guidance issued in the White Paper "Better Services for the Mentally Handicapped (DHSS, 1971), whose main objectives were to bring about a reduction of about one half in the number of hospital beds for people with a learning disability and to expand local authority places in community settings.

Between 1969 and the early 80's admission to longstay care at Lynebank Hospital was often the residential placement of choice by medical and other professional staff. Prior to 1987 there was little alternative residential provision in Fife for people with a learning disability, with 92% of people in staffed residential care being in hospital (Baker and Urquhart, 1987). The plan in 1987 to move a number of residents from Lynebank Hospital to community establishments was financed by

Fife Health Board through closure of a small hospital for people with learning disabilities in 1987 and with money released from ward closures. A group of approximately 100 residents (the number being somewhat flexible) were to move over a three year period to the care of the Social Work Department. The philosophy underpinning the discharge programme was to allow people with a learning disability to live in local community settings near family and friends. The prevailing view was to locate people in 'small homes' with no more than 4 people where at all possible. The discharge programme was aimed at adults aged 18 years and over as separate plans were being developed for the very small number of children still resident in hospital. No specific criteria were laid down regarding discharge although the programme aimed to provide community placements for people with severe and profound levels of disability as well as those who were 'more' able. No formal assessments were carried out with a view to identifying suitability for discharge or potential for improvement. At the time of the study those excluded from consideration for discharge were deemed to have medical and nursing needs requiring a hospital setting (approximately 40 of the 300 residents, c.f. Whoriskey, 1987).

A multidisciplinary team within the hospital (medical, clinical psychology, nursing, physiotherapy, speech therapy and social work staff) identified those residents to be discharged first. The research team had no direct involvement in the process of selection.

The Fife discharge programme reflected the national trend for the 80's and 90's and the impact of 1990 NHS and Community Care Act to reduce the number of people with learning disabilities living in hospital settings with the ultimate aim of full hospital closure. While a number of hospitals south of the border had already been closed with many more planning to close the pace of 'discharge' and closure in Scotland has been somewhat slower. In England and Wales the hospital population had decreased from 60,866 in 1967 to 38, 651 in 1984, a decrease of 36%. In Scotland the change has been somewhat slower, with a decrease of 15% from 6,989

in 1967 to 5,963 in 1984 (OHE, 1986). The Fife discharge plan was the first major project of this type in Scotland.

The present study arose from the opportunity provided by the discharge programme and received support from both Fife Health Board and Fife Regional Council. An application for funding to the Scottish Office Home and Health Department was successful and allowed for the appointment of 2 research assistants for a 4 year period with additional funding by Fife Health Board for a further 2 years. Approval for the study was given by the Fife Health Board Ethical Committee.

Inevitably with a study like this a number of delays with discharge arrangements, and the identification of suitable accommodation in the community, led to the study taking longer than was originally anticipated. A delay was experienced in 1988 when no discharges took place, due to complex financial negotiations between Fife Health Board and the Social Work Department. However, the opportunity afforded by this strengthened the longitudinal component of the research with data collection continuing over a 5 year period.

Participants

Identification of Subjects and Controls

Participants in the study were 100 people with a learning disability resident in Lynebank Hospital at the beginning of the project. The first 50 people identified for discharge from the hospital from our starting date were the 'subjects' with a further 50 people, who were not leaving the hospital at that time, selected as 'controls'. The process of matching 'subjects' with 'controls' was time consuming. However an assessment of skill level, level of disability, medical condition and behaviour had been carried out on all hospital residents in 1987 (Whoriskey, 1987) and updated two years later (Whoriskey, 1989). This allowed for the identification of specific individual profiles and enabled a number of variables to be matched to assist in the identification of people remaining in hospital as possible 'controls'.

While earlier research on deinstitutionalisation found little evidence of a consistent relationship between individual characteristics such as age, length of hospitalisation, level of disability and successful outcome (cf. McCarver and Craig, 1974), there has been a recent call for research to begin to identify individual factors which may account for individual variation in people's responses to the move from hospital to community (Emerson and Hatton, 1994). To take account of the above and to allow appropriate comparison to other similar research studies (e.g. Beswick, 1992; Davies, 1988; de Kock et al, 1988; Felce et al, 1987) subjects and controls were matched on the following variables:-

- Gender
- Age (within 5 years)
- Length of hospitalisation (less than 5 years; 5-10 years; 10-20 years; over 20 years)
- Adaptive behaviour [using overall scores from the Adaptive Behaviour Scale (Nihara, Foster, Shellhaas and Leland, 1974)]
- Diagnosis (ICD 10 classification)

Every effort was made to identify a 'best' match between subjects and controls. However, not all subjects and controls could be matched on all criteria so, for example, some subjects classified as 'mildly retarded' (medical diagnosis) have controls classed as 'borderline'. It was found during the course of the project that some people who were initially controls would be chosen for discharge and hence become subjects necessitating the introduction of a new control person to ensure that the numbers in the control and subject group stayed as near equal as possible.

Tables 7, 8 and 9 present the characteristics of the 100 participants. As well as information on gender, age, length of hospital care and diagnosis, scores for Part 1 of the Adaptive Behaviour Scale are given.

At the first assessment participants ages ranged from 20 to over 60 (mean 39.8 years, median 38 years for subjects and mean 41.5 years, median 37 years for controls).

The majority were between 31 and 50 years (58% subjects, 64% controls). The age distribution for participants included in the study reflected the general age distribution within the hospital at the time (Whoriskey, 1987).

There were 28 males and 22 females in each of the subject and control groups.

As no reliable IQ measures were available level of disability was based on medical diagnosis, (ICD 10 classification, WHO 1992) covering the range mild to profound retardation. 66% of subjects and 64% of controls were described as moderately or severely retarded which compared to the total hospital population profile with just under 60% within the same categories (Whoriskey, 1987). It is of relevance to note that Lynebank Hospital had a higher proportion than average of residents with 'low ability' when compared to other Scottish Hospitals (Baker and Urquhart, 1987).

Most of the participants had been in institutional care for considerable lengths of time. For subjects the mean length of hospital stay was 21.7 years and 20.5 years for controls.

Table 7

Subject/Control Characteristics - Age,
Length of Hospitalisation, Level of Disability

	SUBJECTS N= 50		CONTROLS N=50	
Age (Years)	**No.**	**%**	**No.**	**%**
20-30	11	22	7	14
31-40	19	38	23	46
41-50	10	20	9	18
51-60	6	12	5	10
60+	4	8	6	12
mean and SD	**39.8 (12.59)**		**41.6 (12.60)**	
median	**38**		**37**	
Years in Hospital				
Under 5	2	4	0	0
5-10	2	4	6	12
11-15	4	8	9	18
16-20	20	40	14	28
21-25	8	16	7	14
Over 25	14	28	14	28
mean and SD	**21.3 (8.4)**		**20.5 (8.3)**	
median	**20**		**20**	
Diagnosis				
Borderline	0	0	3	6
Mild	11	22	14	28
Moderate	26	52	21	42
Severe	7	14	11	22
Profound	3	6	1	2
Unspecified	3	6	0	0

Adaptive behaviour was assessed by the Adaptive Behaviour Scale (Nihira et al, 1974). Both subject and control groups showed a wide range in adaptive behaviour functioning with a mean score (Part 1) for subjects of 178.8 (median 193) and for controls of 172.3 (median 190).

Table 8

Subject/Control Characteristics - Summary of Total Scores
on the Adaptive Behaviour Scale (ABS) Part 1

TOTAL ABS SCORES	SUBJECTS	CONTROLS
RANGE	49-247	42-268
MEAN	178.8 (50.3)	172.3 (54.5)
MEDIAN	193	190
% < 140	18	22
% 141-220	66	66
% > 220	16	12

The range of scores supports the view that the groups represented a broad range of abilities.

Detailed information on individual participants is contained in Appendices 7 and 8.

Table 9

Subject/Control Characteristics - Summary of Scores on the Adaptive Behaviour Scale - by Individual Domains

DOMAIN		SUBJECTS	CONTROLS
Independent Functioning	mean	75.5	72.3
	SD	21.0	20.9
Economic Activity	mean	4.4	4.2
	SD	3.2	3.1
Language Development	mean	21.4	22.5
	SD	8.3	9.9
Socialisation	mean	17.3	17.0
	SD	4.8	6.0
Domestic Activity	mean	8.0	7.5
	SD	4.6	4.7
Physical Development	mean	21.0	21.02
	SD	3.1	3.8
Numbers and Time	mean	4.5	5.5
	SD	3.7	3.8
Vocational Activity	mean	8.3	7.4
	SD	3.8	4.3
Responsibility	mean	3.9	3.4
	SD	2.0	2.2
Self Direction	mean	14.0	13.1
	SD	5.4	5.5

On the basis of this information it is clear that the subject and control groups were well matched on the identified variables.

The application of the ICD 10 (WHO 1992) classification to identify level of retardation was less consistent between groups. While 44% of subjects and controls were matched exactly on level of retardation, and a further 50% were matched within one level, a small number, 6%, yielded a discrepancy of 2 or more levels. For

the purpose of the present study adaptive functioning is therefore considered a more robust measure with regard to assessment of 'ability'.

Participant Consent

Once a subject and his/her control had been identified for inclusion in the study efforts were made to seek valid consent from each person. Given the level of disability and communication difficulties of some individuals, the issue of consent had to be tackled in more than one way. The importance of involving 'users' in a meaningful way in such evaluations cannot be underestimated and should not be given lip service only. Ethical issues can arise particularly when a study such as this involves a control group. There is a danger that expectations for discharge are raised for individuals involved in the study and this and other issues required to be handled sensitively. Staff also feel vulnerable and can have mixed views about discharge programmes and their future role (Wing, 1989). Given their close involvement with residents and possible influence, the author recognised the need to inform and involve staff appropriately and seek their support in the assessment of 'participant consent'.

Where applicable an interview took place with the identified 'participant' and the researcher with a member of nursing or social work staff present, usually the key worker. The interview took place in a setting the resident felt comfortable in - usually their ward. The purpose of the study was explained and participants were encouraged to ask questions about the study. For those identified for discharge, the interview was seen as one of the many discussions they were now involved with about their 'new house' in the community. However, as noted earlier, for participants identified for the control group care had to be taken not to raise expectations regarding imminent discharge.

For participants who were unable to give verbal consent themselves because of their level of disability and difficulty in communication a member of nursing or social work staff who knew the resident well would give consent on their behalf. Medical

opinion was also sought for all participants identified for the study as to the appropriateness and effect of their involvement in the study. A consent form was completed for each individual and is contained in Appendix 9.

At any time, if a participant indicated either verbally or non verbally (e.g. by walking away from the researcher, upset at being involved, etc.) that he/she was not wishing to be involved in the study, then this was acknowledged as valid and their involvement in the study was discontinued.

Two people said they did not want to take part in the study from the outset. Another person opted out after the first assessment and these data were not included. Finally, one participant at Assessment 3 (12 months) indicated her wish not to be involved by her non verbal behaviour, in so far as she left the room when the researchers were present and became distressed when asked questions, and her involvement was discontinued at that stage.

Settings

Hospital

The hospital is a purpose built building accommodating approximately 300 longstay residents at the onset of the study. It is situated within its own grounds on the outskirts of the nearby town. There is good access to local shops and facilities.

There were 16 wards in total all of similar style and design except for one ward which had been built in 1986 for children and was intended to be more homely and domestic.

Participants identified for the study were resident in 11 different wards, each with between 18 and 24 residents. All wards were single sex and of the traditional institutional design comprising of large day area, large dining area and dormitory style bedrooms with separate toilet and bathroom facilities. The washing and

bathing facilities were communal. There were very few single bedrooms available and most residents shared their bedrooms with 3 to 5 others.

While all wards were similar they varied a little in the extent of their furnishings and decor. Wards for residents with more severe disabilities tended to be more spartan with few domestic style furnishings. Residents were not involved in choosing decor and furnishings in the ward although a small number had 'personal' furniture in their bedroom area. Some links have been established between quality of physical environment and quality of life for residents although it is more likely to be only one of a number of variables involved.

Meals were provided from a central kitchen and while all wards had a small kitchen area, residents did not generally have access to this. Domestic staff were employed to clean and do other household tasks which were not undertaken by nursing staff. Staffing levels varied across wards with a minimum of 2 to a maximum of 8 on at one time - the number of staff generally relating to dependency needs of residents. The ratio of trained to untrained was in the region of 50/50 across the hospital.

Residents had little choice with regards to selection of meals and in some of the wards nursing staff selected meals for the residents on the previous day.

In its management and organisation the hospital tended towards institutional rather than resident orientated management practices as described by King, Raynes and Tizard (1971).

Community Residences

The subjects in the present study moved to a range of residential facilities in the community with the majority going to small group homes. Information on the type of residence and number of subjects is displayed in Table 10.

Table 10

Community Placement

COMMUNITY RESIDENCE	SIZE OF UNIT	NUMBER OF SUBJECTS
Staffed Group Home	(N= 3-5)	40
Residential Unit	(N=16-20)	4
Elderly Accommodation	(N=36)	2
Community Carer Placement	(N=3)	3
Own Flat (with staff support)	(N=1)	1
	TOTAL	50

Staff Group Homes

Eleven staff group homes accommodating 40 subjects were included in the study, all managed by the Social Work Department. The houses varied in size accommodating a minimum of 3 to a maximum of 5 residents. The group homes were located in different areas in Fife and selected on the basis of a number of factors such as access to family and friends; suitability of accommodation and area and resident choice. Factors such as community acceptance, while an issue, did not prevent property being sought in areas where objections might have been raised.

A number of the houses were located in large towns while others were in small villages in predominantly rural settings. Access to facilities such as shops, buses, etc. varied across the areas.

The character of ordinary housing had been maintained in design and furnishings, with as few institutional facilities included as was possible to meet statutory requirements such as fire regulations. Each house had a separate living room, dining room and kitchen and each resident had their own bedroom.

Staffing numbers in the houses varied significantly from one to five at any one time. The care staff were responsible for all care, domestic, cooking and day to day house maintenance activity. Residents were encouraged to take part in household activities.

Staff in charge of the household tended to have either a nursing or Social Work background - although many of the staff had no formal training.

Residential Units

Four subjects moved to one of three residential units in the area. Two of the units were purpose built while the third was an older building adapted for residential use in the 1960's. The units were located in local towns with good access to shops and other facilities. The accommodation ranged in size from 15 to 20 places and approximated the style of ordinary housing. In most cases residents had their own bedroom or shared with one other. There was 24 hour staffing consisting of care staff, domestic staff and outdoor staff (a gardener for one of the units). As with the staffed group homes the officer in charge of each unit had a nursing or social work background with other staff having a range of qualifications and experience.

Elderly Accommodation

Two of the subjects moved to residential homes for the elderly referred to as Part 4 accommodation in Scotland. The units varied in style, one a purpose build modern unit and the other an older property modified and adapted over the years. The units catered for approximately 32 - 36 residents at any one time.

While there were efforts to provide more homely environments, in many cases residents did share bedrooms and had little access to private day areas. The staffing, on average, tended to be based around a ratio of one member of staff to 7 residents, although there were variations to this at different times of the day.

Community Carers

As in other parts of the country schemes involving 'sheltered lodging' were considered for some people with a learning disability. Three of the subjects moved to this type of setting which involved living in a domestic house with 'landlady' support. Residents were encouraged to take part in domestic activities i.e. preparation of meals, etc.

Own Flat

One subject moved to a flat of his own with carer support. Staff, attached to one of the group homes provided support on a daily basis.

No subjects returned to hospital during the course of the study.

Procedure

Subjects left the hospital at intervals over a three year period as placements in the community became available. While, ideally, all subjects would have moved in time to allow follow up of 2 years or more, delays in acquiring suitable accommodation and in funding led to a decreasing number of subjects at the later stages of follow-up. However, for some a 30 month follow-up was possible.

At the first and second data collection point (T1 and T2) there were 50 subjects and 50 controls. The first assessment (T1), identified as Baseline, took place prior to subjects leaving the hospital with the next assessment (T2) taking place 6 months later. At 12 months (T3) the subject group had dropped by 1 and the control group by 2. Thereafter the control group declines more in relation to the subject group as some of the controls for the subjects had also moved during the period (as explained earlier). Table 11 provides details below.

Table 11

Number of Subjects and Controls at Each Data Point

Assessment Number	Time (in months)	Subjects	Controls
1	0 (Baseline)	50	50
2	6	50	50
3	12	49	48
4	18	39	34
5	24	36	31
6	30	28	21

The individual characteristics of subject and control groups at each assessment are displayed in Table 12 below.

Table 12

Subject/Control Characteristics - Mean Scores and Standard Deviations (in parentheses) for Age, Length of Hospitalisation and ABS (Part 1) at Each Assessment

	SUBJECTS				CONTROLS			
Assessment Number	Nos.	Mean Age	Mean Length of Hospitalisation	Mean ABS (a total)	Nos.	Mean Age	Mean Length of Hospitalisation	Mean ABS (Part 1)
T1	50	39.8 (12.6)	21.3 (8.5)	178.8 (50.3)	50	41.6 (12.6)	20.5 (8.3)	172.2 (54.5)
T2	50	39.8 (12.6)	21.3 (8.5)	178.8 (50.3)	50	41.6 (12.6)	20.5 (8.3)	172.2 (54.5)
T3	49	39.9 (12.7)	21.4 (8.6)	177.6 (50.0)	48	41.0 (12.2)	20.5 (8.5)	170.1 (54.4)
T4	39	40.3 (13.0)	21.0 (9.0)	181.3 (46.8)	34	41.0 (12.3)	20.6 (8.5)	168.5 (55.1)
T5	36	39.8 (12.8)	21.0 (9.0)	180.0 (46.2)	31	41.8 (12.7)	19.9 (8.7)	167.4 (55.6)
T6	28	38.9 (12.0)	21.0 (9.0)	174.1 (50.1)	21	40 (11.6)	21.2 (8.2)	159.3 (60.0)

Data are presented for each group as a whole, with the means calculated from the different numbers in each group at each data point.

Given the differing numbers of subjects and controls from 12 months onwards it was necessary to ensure that we were dealing with roughly similar groups with respect to the matched variables of age, level of disability, etc. Otherwise any changes found in groups over time could be explained by the fact that the 'groups' under study differed at different data collection points (i.e. subject group at T6 was not representative of subject group at T1).

The Friedman Two Way Analysis of Variance by Ranks (Siegel, 1956) was calculated to test the null hypotheses that the subject group was drawn from the same population over Assessment 1 to 6 and similarly calculated for the control group.

Chi square and significance levels for variables under examination are presented in Table 13. This shows no significant differences within subject and control groups on the matched variables.

So, although the number of people from whom data were collected at Assessment 6 (30 months) is fewer that the number at Assessment 3 (12 months), the subject group and control groups remain similar on characteristics such as age, length of hospital stay and baseline adaptive behaviour.

Table 13

Chi Square and Significance Levels for Subjects and Controls for Age, Length of Hospital Stay and ABS (Part 1 Total)

	SUBJECTS		CONTROLS	
AGE	Chi-Square	Significance	Chi-Square	Significance
	1.3061	.93 (NS)	.6395	.99 NS
LENGTH OF HOSPITAL STAY	.9031	.97 (NS)	1.7823	.88 NS
ABS (Part 1 Total)	.7500	.98 (NS)	1.9252	.86 NS

Outcome Measures

The selection of measures for the study was based on a number of factors, not least, the impact of resources available and constraints of an evaluation in natural environment settings. However, the choice of measures employed largely related to the key research questions posed by the study and an attempt to gain as wide a picture as possible of participants' lives and lifestyles over the period under investigation. Measures selected allowed for

- appropriate comparisons to other similar studies carried out in the UK and elsewhere;
- certain variables to be studied over a period of time and with a large group to allow the identification of immediate effects of relocation and the effects of remaining in hospital. This area is of considerable importance given that the vast majority of research undertaken prior and subsequent to this study has addressed only short term effects of resettlement (c.f. Hatton and Emerson, 1996) and often with a small number of participants (c.f. Emerson and Hatton, 1994);
- inclusion of areas which have received scant attention in the literature (e.g. opinions of service users, psychological well-being);
- attention to both the objective and subjective dimensions of quality of life;
- attention to the concept of social validity (Schwartz and Baer, 1991) in the assessment of "quality of life".

Copies of all the measures used are contained in Appendices 10-23.

In attempting to address the complex issue of quality of life and its measurement- three main areas were identified for the purpose of the present study.

- Competence and Personal Growth;
- Health and Well-being; and

- Quality of Care (encompassing lifestyles, environmental issues and management practices).

A total of 14 measures were employed and are described fully below.
Table 14 provides summary information.

TABLE 14

Measures Used in the Study

I	**Competence and Personal Growth**	
1.	Adaptive Behaviour Scale	
2.	Direct Observation of Community Living Skills	
3.	Confidence in Own Community Skills	
4.	Staff Rating of Social Skills	
5.	Staff Rating of Interpersonal Skills	
6.	Self Rating of Interpersonal Skills	
II	**Health and Well-being**	
7.	General Health Questionnaire	
8.	Zung Anxiety Scale	
9.	Zung Depression Scale	
10.	Eysenck Withers Personality Inventory	
11.	Morale and Life Satisfaction	
III	**Quality of Care**	
12.	Assessment of Physical Environment	
13.	Assessment of Individual Lifestyles	
14.	Personal Presentation	

Competence and Personal Growth

Increasing the competence, abilities and skills of people with learning disabilities provided one of the most important rationales during the early stages of the replacement of hospitals with smaller community based forms of residential care (c.f. Emerson and Hatton, 1994). A plethora of measures are available which purport to examine these areas. For the purpose of the present study, measures were selected which aimed to provide a range of information on a number of different aspects of behaviour and skill level from both staff and participants.

Adaptive and Maladaptive Behaviour

This area has probably received most attention in the literature (c.f. Hatton and Emerson, 1996) with measures of adaptive and maladaptive behaviour being most often employed (Emerson, 1988). The research, however, remains equivocal about the short and long term effects of relocation on adaptive behaviour (e.g. Beswick, 1992; Felce, 1989; Hemming et al, 1981; Larson and Lakin 1989; Shah and Holmes, 1987) with maladaptive behaviour considered by some to be the most important cause of failure of community placement (e.g. Intagliata and Miller, 1982; Pagel and Whitney, 1978).

A measure of adaptive and maladaptive behaviour was considered relevant to enhance the body of information already available and allow for appropriate comparisons to be made with other studies.

The instrument of choice was the A.A.M.D. Adaptive Behaviour Scale (A.B.S.) (Nihara et al, 1974) because of its wide availability and acceptability. It is well standardised and validated. The assessment of an individual's adaptive and maladaptive behaviour is carried out by interviewing staff and completing a standardised checklist. The Adaptive Behaviour Scales consist of two sections - Part 1 which is concerned with the assessment of adaptive behaviour and Part 2 which assesses maladaptive behaviour.

Part 1 is organised along developmental lines and is designed to evaluate an individual's skills in ten behaviour domains considered important to the development of personal independence in daily living. The ten behaviour domains are

- Independent Functioning
- Physical Development
- Language Development
- Economic Activity
- Numbers and Time

- Domestic Activity
- Vocational Activity
- Self Direction
- Responsibility
- Socialisation

An overall score for adaptive behaviour is reached by adding together the scores from the individual domains. Part 2 of the scale is designed to provide measures of maladaptive behaviour related to personality and behaviour disorders.

Community living Skills

A range of skills were assessed directly by observing participants in a number of everyday situations such as road crossing, use of public transport, shopping, etc. It was felt important to gather information about some aspects of everyday behaviour in the community by direct observation in order to provide a broader base of information to that obtained directly from staff perceptions of participants' competence. It was also considered a more sensitive form of measurement to some rating scales and would allow small changes in a participant's repertoire to be identified.

The protocol followed had been used by other researchers in Scotland (Lindsay, 1986) to assess the impact of a skills based training programme for individuals with learning disabilities. While participants in the present study were not offered systematic training in these areas - the effects of relocation on individuals' skills levels was one of the areas under investigation.

The assessment involved direct observation of participants on each of 6 tasks. Each task was divided into 6 components and a score of 1 given for each component which could be carried out unaided by the participant. The present study also incorporated a "novel" approach in an effort to gain participants' perception of their own competence. No published study on the effects of relocation had previously

encompassed this aspect (c.f. Emerson and Hatton, 1994) and it was considered very relevant to seek information from participants themselves in assessing their competencies. This was carried out in a one to one interview between the researcher and the participant.

Social Skills

Studies have found that use of community facilities and participation in community activities by people with a learning disability is often limited (e.g. Parameter, 1988; Amado, 1988; Seager, 1990) despite the assumption that community based residential placements would naturally lead to increased participation in community activities and increased utilisation of community resources. Studies have pointed to a difference in the level of social skills and behaviour of people with a learning disability which can impede social integration (e.g. Donnegan and Potts, 1988; Raploy and Firth, 1986; Sigelman et al, 1981). It was therefore considered relevant to include measures of social and interpersonal skills in the study and to assess these areas from both a 'carer' and individual participant point of view.

Social skills were assessed using three scales devised specifically for this project but based on instruments already being used within the services adapted from rating scales developed by Spence (1982) for use with people with a learning disability. Two of the scales involved direct care staff rating of participants' verbal and non verbal behaviour such as their eye contact, quality of speech use, of gestures, etc. and their interpersonal skills such as the extent to which they had friends, how they dealt with teasing and whether they smiled and laughed appropriately.

The third scale involved participants' rating their own interpersonal skills using a simple yes/no format in a structured interview with the researcher. Although there is a degree of overlap in the three scales, it was felt important to address the issue of 'social' skills on as broad a front as possible.

Health and Well-being

Scant attention has been given to the health and well-being of people with learning disabilities in general, and in particular as it relates to changes for people brought about by moving from hospital to community settings and for those remaining in hospital. It was considered relevant to include some measures that related to this facet of quality of life. In reviewing the literature, there appeared to be little available that has been developed for use with people who have a learning disability. However, some work has been done using rating scales such as the General Health Questionnaire and Zung Anxiety and Depression Scales for the assessment of mental health and psychological well-being in this group (Lindsay and Michie, 1988; Prout and Schaefer, 1985). A total of five measures were used to assess this area of quality of life.

Four of the measures selected and described below were felt to give an opportunity to assess broad health indicators.

General Health Questionnaire GHQ 30 (Goldberg, 1978) This questionnaire was designed to be a self administered screening test aimed at detecting psychiatric disorders among respondents in community settings. The GHQ 30 consists of four sub-scales each covering somatic symptoms, anxiety, social dysfunction and depression. Each question asks whether the respondent has recently experienced a particular symptom or item of behaviour on a scale roughly from "less than usual" to "much more than usual". A score of 0 is recorded for questions answered as "less than usual" and "no more than usual", while a score of 1 is recorded for responses of "rather more" or "much more" than usual.

The instrument has been shown to be reliable and valid with a range of populations (Bridges and Goldberg, 1986; Goldberg, 1978; Goldberg and Hillier, 1979).

Zung Depression Scale (Zung and Durham, 1965). This scale was designed to be a self administered test to assess the presence and severity of a depressive disorder. The scale consists of 20 items, 10 of which are worded symptomatically positive, and 10 symptomatically negative. Respondents are asked to rate each of the 20 items as to how it applied to them at the time of testing, in the following four quantitative terms:- a little of the time, some of the time, a good part of the time, or most of the time, scoring from 0 to 3 for each item. This scale has been shown to be a reliable and valid instrument for assessing depression (Gabrys and Peters, 1985; Jonghe and Beareke, 1989).

Zung Anxiety Scale (or Anxiety Status Inventory ASI) (Zung, 1971). This is similar in design to the depression scale and designed to assess the presence and severity of an anxiety disorder. The scale consists of 20 items and respondents are asked to rate each item as to how it applied to them at the time of testing in the same quantitative terms as the depression scale.

Eysenck Withers Personality Inventory (Eysenck, 1967). This measure was designed for use with people with a moderate to mild learning disability to assess personality stability. There is some reported evidence that these personality factors are relevant to community adjustment (Eysenck, 1965). The inventory is a development of the Eysenck Personality Inventory (1964) for adults and the Junior E.P.I. (Eysenck, 1965) for children. The inventory consists of 52 items - 20 Extroversion (E); 20 Neuroticism (N) and 12 Lie (L) items. Items are scored using a yes/no format. Reliability is reported as adequate (Eysenck, 1967) for the three scales.

Morale and Life Satisfaction . The fifth measure used related to the subjective evaluation of satisfaction of participants. In particular it was considered crucial to gain subjective measures of quality of life from participants in addition to the more objective measures available (e.g. Borthwick and Duffy, 1992; Felce and Perry, 1996; Schalock et al, 1990). This was assessed using a questionnaire on morale and life satisfaction already being used in another UK wide project (PSSRU study -

Cambridge and Knapp, 1988) and based on a questionnaire designed by Seltzer and Seltzer (1983) to assess clients' satisfaction with their living circumstances in the community. It comprised a combination of yes/no questions and open ended questions covering issues such as how happy a person felt about their living arrangements, occupation, etc. As with the other measures seeking participant opinion, this was carried out on a one to one basis with the participant.

All of these scales required respondents to comment on their feelings and experiences. Questions were put to participants in a structured interview format with the researcher noting responses and rating the scales accordingly. While the GHQ and Zung scales are designed to be self administered this was not feasible or appropriate for the group under study.

Quality of Care

While all measures employed in the study aimed to assess areas concerned with overall quality of life - specific attention was given to both quality of service and the quality of life of its recipient (c.f. Osborne, 1992).

Few studies have approached the assessment of quality of life of adults with a learning disability by going direct to the client group (c.f. Emerson and Hatton, 1994) although it is now recognised that with care it is practical to involve these individuals in research and service evaluation (eg Beswick, 1992; Flynn, 1989).

Quality of Physical Environment and Lifestyles

Given the relevance of environmental factors and lifestyles within the normalisation philosophy, an assessment of the physical environment of residences, management practices and lifestyles of participants was undertaken. This has been the subject of examination in a number of studies and various instruments and rating scales have been used (eg Felce et al, 1988; Raynes, 1987; Wolfenberger and Glenn, 1975).

Two specific scales were devised for use in the present study based on the 'Checklist of Standards' which had been prepared by the National Development Group (1980) and the Index of Physical Environment described by Raynes, Pratt and Roses (1979). The development of these measures is described earlier in Chapter 5. The social validity of the measures have been examined against 'a general population' sample and a sample of people with a learning disability.

The assessment of physical environment and management practices contains 44 items dealing with issues pertaining to aspects of the physical environment such as access to local facilities, privacy, safety, material environment and staff management.

The assessment of Individual Lifestyle consists of 46 items dealing with issues pertaining to patters of daily life, access to services, personal possessions, visiting and contact by family and friends, independence and choice. Items were scored as 1 or 0 dependent on the presence or absence of specified criteria.

The two measures were administered to care staff in an interview format. Staff completing the questionnaire were required to have known the individual for at least 6 months.

Personal Presentation Checklist

This checklist was developed by PSSRU specifically for the evaluation of the English Care in the Community Demonstration Programme (Cambridge and Knapp, 1988). It assesses the physical appearance of the respondent across a range of dimensions including clothing and posture (scored from 0 - 5), appearance and unusual traits (scored from 0 to 6). Higher scores indicate a less unusual appearance. Although the completion of the checklist involves implicit value judgements about what is and is not culturally acceptable, the checklist in general, provides a useful means for assessing deviations from so called 'normal appearance' which are said to have implications for successful integration within communities.

Reliability of Measures

With the exception of the ABS and the Eysenck-Withers Personality Inventory for which there are published reliability data - reliability was calculated for all other measures on a sample of at least 10%. Inter-rater and inter-respondent data were collected on the remaining interview measures and inter-rater reliabilities were calculated for the direct observational methods used. These data are shown in Table 15.

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With regards to the ABS, Speat (1982) reported adequate test-retest and inter-rater reliabilities for individual domains. Nihira et al (1975) reported mean reliability on the ABS for Part 1 (adaptive behaviour) of .86 and a mean reliability for Part 2 - (maladaptive behaviour) of .57. Eysenck (1967) reports reliability for the three scales of Eysenck Withers Personality Inventory for Extroversion = .70; Neuroticism .88 and Lie Score = .70.

The General Health Questionnaire and Zung Scales have been used almost exclusively with non learning disabled people and reliability of these instruments has been referred to earlier in this chapter. It was considered appropriate to calculate reliability for these measures given the context in which they were being used.

Table 15

Inter-rater and Inter-respondent Agreement on a 10% Sample of the Data Obtained from Measures Used

MEASURE	*MEAN PERCENTAGE AGREEMENT BETWEEN OBSERVERS/RATERS*
Direct observation of Community Living Skills *	94%
Staff rating of social skills +	80%
Staff rating of interpersonal skills +	77%
Self rating of interpersonal skills *	100%
Confidence in own community skills *	89%
General Health Questionnaire *	80%
Zung Anxiety Scale *	38% absolute (69% within 1 point)
Zung Depression Scale *	18% absolute (50% within 1 point)
Morale and life satisfaction *	89%
Personal presentation *	100%
Quality of Physical Environment +	81%
Quality of lifestyle +	85%

* shows inter-rater agreement + shows inter-respondent agreement

Reliability estimates were obtained on 10% of the data during the course of the study. A total of 490 either inter-rater or inter-respondent agreements were made over the research period. Inter-rater reliabilities are concerned with the extent to which different raters (the research assistants in this study) recorded the same information, either from the same respondent at different points in time in the case of interview data, or of the same events at the same point in time in the case of observational recording of behaviour. Inter-respondent reliabilities are measures of the agreement that different respondents (care staff) have about what they are asked to report. Inter-rater data were collected by having two research assistants rate an individuals' behaviour at the same time when direct skills were being observed - or two research assistants interviewing the same individual independently but within a week of each other. Inter-respondent data involved two members of nursing staff in the hospital and two care staff in the community completing the relevant questionnaire on a particular individual, independently. Efforts were made to ensure that this information was collected within the same week.

Percentage agreements were calculated by dividing the lower score by the higher score and multiplying by 100.

In a study of this nature where many measures are employed and information is collected repeatedly at different points in time by different research assistants a reasonable level of reliability is aimed for. For most of the measures 80% is commonly accepted by researchers as indicating a satisfactory level of inter-rater reliability (Harrop et al, 1989).

However, for the Zung Anxiety and Depression Scales absolute reliability was very low. When taken within 1 point - reliability increased but still fell below the 80% mark. All other measures except self-rating of interpersonal skills achieved 80% agreement or more. The reliability of measures excluding the Zung Scales is considered adequate.

Variability of Measures Employed

While the study aimed to assess all the participants on all of the measures, because of the range in ability of the subjects and controls involved in the study, some measures were not appropriate to a number of the participants. This was because some of the participants were too disabled to be assessed independently on, for example, road crossing skills, or lacked the verbal ability to answer questions appropriately. All participants at every assessment point (i.e. assessment 1-6) were involved in the following measures

- Adaptive Behaviour Scale
- Staff rating of social skills
- Staff rating of interpersonal skills
- Personal presentation
- Assessment of lifestyle
- Assessment of physical environment

However, not all participants were able to provide responses to questions on the following measures

- General Health Questionnaire

- Zung Anxiety and Depression Scales
- Morale and Life Satisfaction
- Self rating of interpersonal skills
- Eysenck Withers Personality Inventory
- Confidence in own community skills

or to participate in the direct observation of community living skills

The number of participants involved for each measure at assessments 1-6 is shown in Table 16.

While, in general, the number of subjects and controls assessed on these measures decreased over time, with the overall decline in numbers, the number of subjects increased between assessment 1 and 2 on some of the measures, notably the Zung Scales, GHQ, Eysenck Withers Personality Inventory, Morale and Life Satisfaction Direct Observation of Community Living Skills and Confidence in Own Community Skills. The reason for this arose as some subjects were discharged at the very beginning of the study before all baseline measures could be obtained. This was outwith the control of the research team.

The measures used directly with participants varied a little regarding the level of responses required. As a result some participants were able to respond to some measures and not to others - hence there was not an equal number of subjects and controls for each measure. The Eysenck Withers Personality Test was one of the more difficult ones to complete and the number of participants responding to this measure decreased significantly at 24 and 30 months - hence no data were included for these assessments. The numbers also dropped for two other measures - confidence in own community skills and the General Health Questionnaire at three months and these data were excluded from the analysis.

However, the relevance of including measures which directly seek participants opinions and feelings balances out the less than ideal numbers involved at each assessment. The study design allowed for group comparisons on different measures

over time and sufficient data were collected to allow for meaningful analysis on all of the measures.

TABLE 16

Number of Subjects (S) and Controls (C) Completing Each Measure

T1-T6

Measure	Baseline		6 months		12 months		18 months		24 months		30 months	
	S	C	S	C	S	C	S	C	S	C	S	C
Adaptive Behaviour Scale	50	50	50	50	49	48	39	34	36	31	28	21
Direct Observation of Community Living Skills	36	37	42	37	41	33	31	24	29	15	20	8
Confidence in own Community Skills	27	32	29	28	30	24	28	20	20	16		
Staff Rating of Social Skills	50	50	50	50	49	48	39	34	36	31	28	21
Staff Rating of Interpersonal Skills	50	50	50	50	49	48	39	34	36	31	28	21
Self Rating of Interpersonal Skills	31	33	31	32	30	29	23	21	22	15	16	13
Zung Anxiety Scale	28	32	31	32	32	27	22	19	18	13		
Zung Depression Scale	30	32	30	32	32	28	21	19	17	13		
Eysenck Withers Personality Inventory	19	22	25	22	24	22	18	14				
General Health Questionnaire	30	34	32	33	31	29	22	19	17	13		
Morale and Life Satisfaction	31	37	37	35	36	32	31	24	29	18	24	17
Assessment of Living Units	50	50	50	50	49	48	39	34	36	31	28	21
Assessment of Individual Lifestyle	50	50	50	50	49	48	39	34	36	31	28	21
Personal Presentation	50	50	50	50	49	48	39	34	36	31	28	21

Data Collection

Data were collected for each participant once an individual was identified for inclusion in the study (baseline). Thereafter data were collected at 6 months, 12 months, 18 months, 24 months and 30 months following discharge for subjects and at similar intervals for the control group. Data were collected for a small number of participants up to 42 months but the numbers reduced to the extent that any analysis would be limited and were therefore not included. It had been hoped that longer term follow up could take place (e.g. 5 years) but the Social Work Department did not support the concept of ongoing evaluation.

Staff in both hospital and community settings were kept informed of the progress of the study by regular newsletters and meetings. This was considered important given the level of staff co-operation required.

The time involved for data collection increased as more subjects were discharged. Each assessment phase necessitated at least 2 and often 4 visits to a community residence to gain the appropriate information from staff and subjects, at times which were convenient to both. Data for each phase were collected within a 2 week period.

Seven measures required staff to provide the information and every effort was made to have the "keyworker" for an individual involved. In all cases information was obtained from staff who knew the person well. On visits to wards and community residences often more that one member of staff was available and the information was gained from discussion with all the relevant parties. The information gained directly from participants was collected using structured interviews and direct observation.

The Best Laid Plans....

Every effort was made to follow the study procedure for all participants but with an evaluation of people in their natural environments some relatively minor problems arose.

In the first few weeks of the study, a small number of participants (N=6) had been discharged before all the baseline data for Phase 1 had been collected. It was possible to collect some information retrospectively but for measures seeking direct views, opinions, etc., of participants (e.g. Zung Anxiety and Depression Scales, Morale and Life Satisfaction, General Health Questionnaires) baseline data were not obtained. However as group sizes were being compared and the overall number for each group did not change significantly from Phase 1 to Phase 2 on these measures, the problem was contained.

As noted earlier, while it was intended to follow up equal numbers of subjects and controls for each data phase, in some cases the identified control became a subject. If this occurred at a very early stage then another control was selected from the remaining hospital residents, on whom a lot of data was already available. For some this was not practical so control data collection ceased.

The numbers in both subject and control groups remained sufficient up until data Phase 6 to allow for meaningful comparisons and analysis. Although matching procedures were adopted data are presented for each group as a whole, with the means calculated from the different numbers in each group at each point.

For some people moves were postponed for varying lengths of time so that assessments were carried out for Phase 1 (baseline) some months before the discharge. The longest delay was 8 months. However, the time between assessing a subject and his/her matched control was kept to a minimum, on average within 8 weeks. There were also some delays in identifying people for discharge which led to reduced numbers from Phase 4 onwards.

CHAPTER 7

RESULTS - STUDY 2

DATA ANALYSIS AND PRESENTATION

Statistical Analysis

Design and Rationale

Data were collected for each participant on the measures described in Chapter 6 at six data collection points over a 30 month period and was collated for subjects and for controls to allow for appropriate within and between group analyses.

The research was organised to allow hypotheses to be tested using two main experimental designs - a longitudinal design using participants as their own controls and a comparative research design. Some problems arose in the implementation of the experimental design regarding the 'matching' of subjects and controls, with the consequent differing numbers of subjects and controls from 12 months (T3) onwards. The main analysis therefore addresses the within group comparisons over time although comparisons are also made between subjects and controls. It has been shown that the groups did not differ significantly at the outset of the study on a number of important characteristics (see Table 13 - Chapter 6).

Results are therefore considered in the following format:

- Within group analysis for subjects - longitudinal design examining the effects of relocation.
- Within group analysis for controls - longitudinal design examining the effects of remaining in hospital.
- Comparative matched subjects design examining any differences between the two groups.

The longitudinal design of the research allowed data to be analysed in two ways.

Firstly, to identify any significant changes over T1 to T6 for subjects and controls, and secondly, the direction of any change and between what time periods. So rather than employing a simple A-B comparison - the analysis can take into account the variance from one assessment to another. The advantage of this method is the

ability to identify relevant changes from T1 to T2, T2 to T3, T1 to T3 etc. which can identify 'early' effects of changes for participants and changes over time.

Analysis

SPSS was the package of choice. As the data generated across a number of the measures were ordinal in nature and as no clear assumptions could be made about the distribution curve - non parametric techniques of hypotheses testing were chosen.

Within Groups

The statistical analysis employed for each measure was a Friedman Two Way Analysis of Variance by Ranks (Siegal, 1956) referred to as the Friedman in the text. With the differing number of subjects and controls at different assessments it was elected to exclude cases with missing values and to use as much of the data as possible.

Follow up to significant Friedman's analysis was by the Wilcoxon Matched Ranks Test (Siegal 1956) comparing each assessment with each other to identify the individual significant differences revealed by the Friedman test.

Between Groups

The Mann-Whitney U test (Siegal, 1956) was chosen to examine any differences between subjects and controls and in this context the groups were treated as independent samples. The analysis was carried out between each assessment phase (e.g. T1 for subjects compared with T1 for controls), T1 - T6 for each variable under investigation.

The Mann-Whitney test is considered one of the most powerful non parametric tests and is a most useful alternative to the t test.

Significance Levels

Given the problem of Type 1 errors being made with multiple comparisons and the experimental hypotheses wrongly supported, the significance of results can be made

more robust by accepting a more stringent level of significance (cf Meddes, 1991). For the present study a significance level of .01 is accepted although all significant results are presented and discussed further.

Data Presentation

The volume of data available makes it impractical to present raw scores in this thesis. Summary data with mean scores and standard deviations (given as an indication of the data) are presented with graphical presentation of the data as appropriate.

Results for the Friedman are presented in the following way: chi-square value; degrees of freedom; and level of significance. Wilcoxon significance values are displayed where appropriate.

Results for the Mann-Whitney are presented as Z scores and P values (2 tailed)

Significance levels are presented as exact (to two decimal points) when greater than .05. Otherwise levels are presented as <.05; <.01; <.001 as appropriate.

Data from Measures Employed in the Analysis

Results are presented by each of the three main groupings of dependent variables presented in Chapter 6.

	Measure	Data Generated
	Competence and Personal Growth	
1.	Adaptive Behaviour Scale	(i) Total score for adaptive behaviour (ii) Total score for individual domains (iii) Total score for maladaptive behaviour

2.	Assessment of Community Living Skills	Total score for each of six conditions (analysed separately for each condition).
3.	Confidence in Own Community Skills	Combined total score for seven areas
4.	Staff Rating of Social Skills	Total score
5.	Staff Rating of Interpersonal Skills	Total score
6.	Self Rating of Interpersonal Skills	Total score
	Health & Well-being	
7.	General Health Questionnaire	Total score
8.	Zung Anxiety Scale	Total score
9.	Zung Depression Scale	Total score
10.	Eysenck-Withers Personality Test	Total for Extroversion, Neuroticism and Lie Scores
11.	Morale and Life Satisfaction	Total score
	Quality of Care	
12.	Assessment of Living Units	Total score
13.	Assessment of Individual Lifestyles	Total score
14.	Personal Appearance	Total score

The results are presented in three parts:-

I Effects of relocation

II Effects of remaining in hospital

III Comparison between movers (subjects) and stayers (controls).

The presentation and analysis of the data is followed by a discussion of the implications and findings.

CHAPTER 8

AN EVALUATION OF CHANGES IN SOME ASPECTS OF QUALITY OF LIFE BROUGHT ABOUT BY THE RELOCATION OF PEOPLE WITH A LEARNING DISABILITY FROM HOSPITAL TO COMMUNITY RESIDENTIAL ESTABLISHMENT

I The Effects of Relocation

II The Effects of Staying in Hospital

III Comparison between 'movers' (subjects) and 'stayers' (controls)

CHAPTER 8

I THE EFFECTS OF RELOCATION

Competence and Personal Growth

The experimental hypotheses were that there would be an increase in competence and personal growth for people moving from hospital into the community.

Results from the six measures used to assess competence and personal growth are presented below.

1) *Adaptive Behaviour Scale (ABS) - Adaptive Behaviour*

Comparison of overall scores of adaptive behaviour for subjects shows that there was almost no change from baseline (T1) and over time up to 30 months (T6). The mean score at T1 was 178.8 (SD 50.3) and at T6 (30 months) was 179.5 (standard deviation 46.7) - a change of less than one point. There was little variation in overall scores at T2, T3, T4 and T5 as seen in Table 17.

Table 17

Adaptive Behaviour Scale (Part 1)
Mean Scores and Standard Deviations
Subjects T1 to T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	178.8	185.8	182.8	183.7	179.5	179.5
SD	50.3	48.7	46.6	42.8	49.0	46.7

Any changes in the overall scores for adaptive behaviour (Part 1) of ABS do not reach statistical significance as examined by the Friedman test (Chi-square 8.5389, D.F.5., P= .07).

Individual Domains (ABS)

Because the overall score of the ABS (Part 1) may mask variations within the individual domains an analysis of these data was undertaken. Of the 10 domains, 7 showed no statistical significance over assessment points, T1-T6. However, for 3 of the 10 domains - numbers and time, domestic activity and economic activity the Friedman test shows significance. Table 18 shows mean scores and standard deviations for these domains.

For Numbers and Time scores rise a little at (T2) returning to almost the baseline score at 30 months (T6). The Friedman test shows significance (Chi-square 17.9521, D.F.5., P <.01), with the Wilcoxon values showing subjects' scores at baseline are lower than their scores at 6 months (P<.01), 12 months (P<.001), 18 months (P<.0001) and 24 months (P<.01), but not at 30 months.

For Domestic Activity scores rise between T1 and T2 with little change thereafter. The Friedman test shows significance (Chi-square 28.911, D.F.5., P <.01) with the Wilcoxon showing subject scores at baseline are lower than their scores at 6 months (P<.001), 12 months (P=.<001), 18 months (P<.01), 24 months (P<.001) and 30 months (P<.01).

Economic activity rises from T1 and again stays relatively stable. The Friedman test shows significance (Chi-square 10.216, D.F.5., P <.05) but not at the more stringent 0.01 significance level with the Wilcoxon showing subject scores at baseline are lower than their scores at 6 months (P<.05), 12 months (P<.001), 18 months (P<.05), 24 months (P<.05) and 30 months (P<.05).

Table 18

Individual Domains
Mean Scores and Standard Deviations (ABS Part 1) for Subjects T1-T6

		Baseline	6 months	12 months	18 months	24 months	30 months
Numbers and Time	Mean	4.5	5.6	5.6	5.5	4.9	4.3
	SD	3.7	3.8	3.7	3.5	3.6	3.0
Domestic Activity	Mean	8.0	11.3	11.5	11.1	11.2	10.1
	SD	4.6	6.0	5.3	4.5	5.4	5.8
Economic Activity	Mean	4.4	6.2	5.9	6.1	6.2	5.8
	SD	3.2	4.8	3.8	4.2	4.2	3.9

For all 3 domains the mean scores rise between baseline (T1) and 6 months (T2), thereafter remaining relatively stable with a slight decline at 24 months (T5) for Numbers and Time and at 30 months (T6) for Economic and Domestic Activity.

Maladaptive Behaviour

Comparison of overall scores of maladaptive behaviour for subjects shows some changes between baseline (T1) and subsequent assessments, up to 24 months (T5). The Friedman test revealed significance but not at .01 level (Chi-square 11.1778, D.F.5., $P < .05$) with the Wilcoxon showing significance between baseline and 12 months ($P<.05$), and 24 months ($P<.05$). Mean scores and standard deviations are displayed in Table 19.

Table 19

Maladaptive Behaviour
Mean Scores and Standard Deviations
Subjects T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	19.1	23.0	24.0	23.3	23.6	18.1
SD	17.8	17.5	12.5	16.5	19.5	13.3

2) *Assessment of Community Living Skills*

As noted in chapter 7, a total score was calculated for each of the six conditions and analysed separately. Comparison of group scores for subjects on a sample of six direct observations of community skills is shown in Table 20. This table points to a small increase from baseline (T1) and subsequent assessments. There are two sets of statistically significant differences in the data. For pedestrian crossing the Friedman test shows significance (chi-square 17.8364, D.F.. 5, $P < .01$) with the Wilcoxon showing scores at baseline are lower than scores at 6 months ($P<.01$), 12 months ($P<.001$), 18 months ($P<.001$), 24 months ($P<.001$) and 30 months ($P<.001$). For shopping the Friedman test shows significance (chi-square 13.3875, $P < .01$), with the Wilcoxon showing scores at baseline are lower than the scores at 12 months ($P<.01$), 18 months ($P<.01$), 24 months ($P<.001$), and 30 months ($P<.001$) with scores at 6 months also lower than scores at 12 months ($P<.05$), 18 months ($P<.001$) 24 months ($P<.01$) and 30 months ($P<.001$).

Table 20

Directly Observed Community Living Skills
Mean Scores and Standard Deviations
Subjects T1-T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Pedestrian Crossing							
	Mean	2.9	3.3	3.7	3.6	3.8	4.1
	SD	1.3	1.4	1.5	1.3	1.7	1.3
Road Use							
	Mean	2.7	3.0	3.1	3.2	3.2	3.5
	SD	1.6	1.5	1.3	1.3	1.5	1.0
Restaurant Use							
	Mean	3.4	3.7	3.7	3.8	3.9	4.1
	SD	1.0	1.1	1.1	0.8	1.0	0.9
Shopping							
	Mean	3.4	3.7	4.0	4.0	4.0	4.6
	SD	1.0	1.0	1.2	0.9	1.0	0.6
Bus Use							
	Mean	1.8	1.6	1.6	1.7	1.8	2.2
	SD	2.1	2.3	2.3	2.3	2.4	2.6
Phone Use							
	Mean	2.2	2.3	2.1	2.4	1.9	1.9
	SD	1.7	2.1	2.1	2.1	2.3	2.3

3) *Confidence in Own Community Skills*

Overall mean scores were calculated for this measure encompassing the seven individual skills. As described earlier in Table 16 the small number of subjects at 30 months (T6) scoring on this measure led to these data being excluded.

Table 21 shows mean scores and standard deviations for subjects. There is very little variation across assessments T1-T5. The Friedman test does not show significance (Chi-square 2.9200, D.F.4., P=.58).

TABLE 21

Confidence in Own Community Skills
Mean Scores and Standard Deviations
Subjects T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Mean	98.0	93.9	101.8	105.1	104.6
SD	27.7	33.5	26.5	19.2	18.3

4) *Staff Rating of Social Skills*

A total score was derived from this questionnaire and used in the analysis. Table 22 shows mean scores for subjects. There was virtually no change between baseline and subsequent assessments following discharge to the community on this measure and analysis reveals no significant differences (Chi-square 6.1462, D.F. 5, P=.19).

Table 22

Staff Rating of Social Skills
Mean Scores and Standard Deviations
Subjects T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	69.6	72.8	70.2	72.2	69.1	69.4
SD	25.6	24.8	25.9	23.2	64.7	64.3

5) *Staff Rating of Interpersonal Skills*

The total scores derived from this measure were used in the analysis. Comparisons of mean scores displayed in Table 23 indicate little change between baseline and subsequent assessments and the analysis does not show statistical significance (Chi-square 3.5952, D.F.5., P= .61).

Table 23

Staff Rating of Interpersonal Skills
Mean Scores and Standard Deviations
Subjects T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	75.5	80.6	79.1	81.7	78.6	80.7
SD	23.7	20.9	20.8	18.2	19.7	21.8

6) *Self Rating of Interpersonal Skills*

As described earlier in Table 16, because of the small number of people responding to this questionnaire at 30 months data are analysed up to 24 months. Comparison of mean total scores indicates a trend towards an increase in how subjects rate their own interpersonal skills between baseline and 24 months. Means and standard deviations are shown in Table 24. The Friedman test does not reveal significance (Chi-square 7.6000, D.F. 4., P=.12).

Table 24

Self Rating of Interpersonal Skills
Mean Scores and Standard Deviations
Subjects T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Mean	26.2	29.2	33.4	32.5	33.1
SD	9.4	8.7	6.4	7.3	4.9

Summary of Findings

The results from the 6 measures used in the present study reflecting the general quality of life indicator of competence and personal growth provide some mixed findings in relation to the subject group.

On the adaptive behaviour scale the results suggest no overall changes in adaptive behaviour following relocation from hospital to community residences up to 30 months following discharge. However, further analysis of the individual domains of the adaptive behaviour scale do reveal some statistically significant differences on numbers and time, domestic activity and economic activity, which are masked when considering the aggregated data of overall adaptive behaviour. The improvements in these areas occur by the first follow up subsequently remaining stable or even declining slightly.

The explanation for this could be that subjects have not necessarily learned new skills but rather have more opportunity to demonstrate these skills in the community as opposed to a hospital environment. It is likely that there is greater opportunity to engage in domestic activities, handle money etc. in a community residence than in an institution.

An interesting picture emerges with respect to maladaptive behaviour with subjects, as a group, showing an increase on this measure at 6 months and subsequent assessments up to 24 months. A number of reasons could be put forward for this increase in maladaptive behaviour following relocation to the community. Firstly, it could represent an initial increase in maladaptive behaviour, because of the move, which then doesn't change. Secondly, the perception of 'problem' behaviour by staff in community residences differs somewhat to that of staff in the hospital so the same behaviour is rated differently in the two settings. A related reason may be that different settings elicit different behavioural responses from participants. However, the overall scores are relatively low.

A sample of community living skills assessed by direct observation found some increases in skills in two areas, pedestrian crossing and shopping between baseline and subsequent follow ups in the community. These changes over time however, may in fact represent changes which are taking place due to participation in the assessment process. As people are involved directly in the assessment of skills incremental learning may be taking place. Subjects could also be becoming familiar with the assessment process and what is expected of them. Small changes which do not reach statistical significance are found for most of the other skills observed. Assessing confidence in own community skills and assessment of interpersonal skills by seeking direct participant views, show no significant change over T1 to T5. A similar trend is found for staff rating of social and interpersonal skills.

It is not the case, however, that changes which are non-significant in the statistical sense are necessarily unimportant. There is a general trend for these measures to indicate small positive differences in favour of the community settings.

In conclusion, any gains found in the area of competence and personal growth for subjects are modest following discharge from hospital to community settings. In most cases any gain in assessed skills level occurs by the first follow up (6 months). The learning curve levels out for all subsequent assessments.

The experimental hypotheses are partly supported by the results demonstrating that subjects who leave hospital show some initial modest gains in certain areas of skill acquisition although for many areas there are no changes as assessed on these measures.

Health and Well Being

The experimental hypothesis was that there would be a positive impact on health and well-being for people moving from hospital into the community.

Results from the 5 measures used to assess health and well being are presented below.

1) *General Health Questionnaire (GHQ 30)*

The mean total scores for the General Health Questionnaire, GHQ, are presented in Table 25 for T1-T4 as there were insufficient subjects completing this measure at T5 and T6 for inclusion in the analysis (see Table 16).

The most notable feature is the low scores at all assessment points which may reflect the difficulty of using such a measure with people who have a learning disability. Statistical analysis reveals no significance (Chi-Square .2571, D.F. 3., P=.97)

Table 25

GHQ (30)
Mean Scores and Standard Deviations
Subjects T1 - T4

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
Mean	1.34	1.10	0.44	1.84
SD	3.33	1.97	1.13	4.5

2) *Zung Anxiety Scale*

Data up to 24 months were included in the analyses. Total scores on this measure were calculated and mean scores for assessment T1-T5 are presented in Table 26.

Table 26

Zung Anxiety Scale
Mean Scores and Standard Deviations
Subjects T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Mean	7.9	6.0	6.7	4.8	4.0
SD	6.0	5.9	7.9	4.3	2.4

The Friedman test reveals no significance (Chi-square 7.2333, D.F. 4., P= .12).

3) *Zung Depression Scale*

A comparison of mean total scores over assessment points shows a downward trend but analysis does not show significance (Chi-square 8.0824, D.F. 4., P= .09). Mean total scores and standard deviations are shown in Table 27.

Table 27

Zung Depression Scale
Mean Scores and Standard Deviations
Subjects T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Mean	12.2	6.4	7.8	4.5	4.2
SD	8.6	6.2	9.4	5.2	6.0

4) *Eysenck Withers Personality Inventory*

Three total mean scores are presented for this measure for Extroversion; Neuroticism and Lie Score and are shown in Table 28. Data for T1 - T4 are included in the analyses.

No significant differences are revealed by the Friedman test for extroversion (chi-square 1.7667, D.F.3, P = .62); Neuroticism (chi-square 2.2500, D.F.3, P = .52) and the lie score (chi-square 1.6167, D.F.3, P = .66).

Table 28

Eysenck Withers Personality Inventory
Mean Scores and Standard Deviations (in parentheses) for Extroversion (E), Neuroticism (N) and Lie Score (L) Subjects T1-T4

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
Extroversion	14.6	14.3	14.6	15.1
	(3.7)	(3.6)	(4.1)	(3.6)
Neuroticism	5.8	5.6	5.1	5.9
	(4.2)	(5.0)	(5.1)	(4.5)
Lie Score	6.0	6.8	7.8	6.8
	(3.0)	(2.8)	(2.9)	(2.6)

5) *Morale and Life Satisfaction*

Comparison of mean scores across T1 to T6 as presented in Table 29 shows that there is a change in the direction of higher scores for assessment T2-T6 compared to T1.

The mean score at baseline (T1) is 16.9 which then increases at 6 months (T2) post discharge to 23.5, thereafter remaining stable and reducing slightly. The Friedman test shows significance (Chi-square 35.1917, D.F.5., P <.001) with Wilcoxon showing scores at baseline are significantly lower than at 6 months (P<.001), 12 months (P<.001), 18 months (P<.001), 24 months (P<.01) and 30 months (P<.001).

Scores at 6 months are higher than scores at 18 months and 24 months (P< .05) with scores at 12 months higher than 18 months (P<.05) and 18 months higher than 24 months ((P<.05).

This can be interpreted as a certain degree of fluctuation over assessment points with the highest level of personal satisfaction found at 6 months and 12 months post discharge. The statistical significant difference is in the predicted direction, and becomes apparent at the first follow up following discharge.

Table 29

Morale and Life Satisfaction
Mean Scores and Standard Deviations
Subjects T1-T6

Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
16.9	23.5	23.3	22.0	21.7	22.0
4.5	2.6	3.9	3.8	4.5	4.3

Summary of Findings

Health and well-being were considered to be important facets of quality of life and five measures were employed to assess changes in these areas following relocation to the community. Results from the General Health Questionnaire, Zung Anxiety and Depression Scales and the Eysenck Withers Personality Inventory revealed no statistically significant changes resulting from people moving from hospital to the community. It is difficult to draw firm conclusions from these results given some possible problems in the use of these measures with people with learning disabilities and the low inter-rater reliability, in particular, for the Zung Anxiety and Depression Scales (see Table 15).

Scoring on most of these measures was low indicating, if anything, low psychiatric morbidity for this group.

Results from the fifth measure - morale and life satisfaction - support the experimental hypothesis and demonstrates that people who leave hospital report significant improvements in their lifestyle and satisfaction following relocation to the community. There is some evidence to suggest that subjects experience an initial postmove improvement followed by a period of readjustment and some decline thereafter - although why scores improve between 24 months and 30 months is unclear. However, the changes when they do occur are small.

Quality of Care

The experimental hypothesis was that there would be an increase in quality of care for people moving from hospital to community residences. Results from the 3 measures used to assess quality of care are presented below.

1) *Assessment of Living Units*

Comparison of the mean scores for subjects presented in Table 30 demonstrates that there is a clear improvement in their living environment once they leave hospital. The Friedman test shows significance (Chi-square 51.4640, D.F.5., $P < .001$) with Wilcoxon values showing scores at baseline are lower than scores at all other assessments (6, 12, 18, 24 and 30 months) ($P<.001$). Wilcoxon values of significance can also be found between 6 and 18 months ($P<.01$), 12 and 18 months ($P<.01$), and 18 and 24 months ($P<.05$). The changes in mean scores over assessments 6, 12, 18, 24 and 30 months seem small but analysis of individual data revealed some reach statistical significance. The quality of physical environment is assessed as being highest at 18 months, decreasing a little again at 24 months, with another increase at 30 months. The measure may be sensitive to small changes taking place at particular points in time in how residential units in the community are being managed. It may not have been possible to detect much further improvement on the measure used because of ceiling effects limiting score progression (maximum score 44).

Table 30

Assessment of Living Units
Mean Scores and Standard Deviations
Subjects T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	23.3	37.6	38.0	38.5	37.8	38.3
SD	4.3	4.1	3.3	3.0	2.9	3.4

2) *Assessment of Individual Lifestyles*

Comparison of total mean scores for subjects presented in Table 31 demonstrates a very clear improvement in their assessed 'lifestyle' once they leave hospital. The improvement is apparent at first follow-up following discharge, mean score at baseline was 39.71 and at 6 months of 52.5. The Friedman test shows significance (Chi-square 38.8012, D.F.5., P <.001) with the Wilcoxon showing differences between baseline and all other assessments (P<.001). Wilcoxon also shows differences between 12 months and 30 months (P<.001) and 18 months and 30 months (P<.01) - with scores at 30 months being lower that those at 12 and 18 months. One possible reason for this could be the sensitivity of the measure in picking up small changes in lifestyle at different points in time.

Table 31

Assessment of Individual Lifestyles
Mean Total Scores and Standard Deviations
Subject T1-T6

Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean 39.7	52.5	53.7	52.7	53.4	49.7
SD 7.5	7.1	6.9	7.0	6.6	7.2

3) *Personal Presentation*

One overall score was derived from this assessment. The mean total scores of the Personal Presentation measure are presented in Table 32. No changes can be found over assessment points with scores remaining constant across both hospital and community settings over time. The maximum score achievable on this measure is 16 and scoring at all assessment points is at, or near, the maximum. The Friedman test reveals no significance.

Table 32

Personal Presentation
Mean Total Scores and Standard Deviations
Subjects T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	15.7	16.0	15.8	15.7	15.4	15.8
SD	0.6	0.2	0.6	0.5	1.0	0.4

Summary of Findings

Three particular areas were looked at under the heading of 'quality of care' as contributing to overall quality of life.

Results from the assessment of living units and of individuals lifestyle support the experimental hypothesis that there is an improvement in these areas for people who move out of hospital to live in community residences. This improvement becomes apparent on discharge and there is a levelling off thereafter. These results could be taken to support the view that people who are relocated to live in the community live in more 'valued' settings than they experienced when living in hospital. The social validity of these measures have been addressed in Chapter 5. The results could also support the view that there is some variation within community settings possibly due to management style or staff attitude and this may be reflected in the significant differences found between some of the assessment points while subjects are in the community.

11 THE EFFECTS OF STAYING IN HOSPITAL

Competence and Personal Growth

The experimental hypothesis was that there would be no change in the area of competence and personal growth for people remaining in hospital.

Results from the six measures used to assess competence and personal growth are presented below.

1) *Adaptive Behaviour Scale*

Comparison of overall scores of adaptive behaviour for controls shows little change from baseline (T1) up to 30 months (T6). There is a small decrease over time with a mean score at baseline (T1) of 172.3 and at 30 months (T6) 160.4 as shown in Table 33. However, the Friedman test does not reveal significance (Chi-square 6.3267, D.F. 5, P = .18)

Analysis of individual domains shows no significant changes.

Table 33

Adaptive Behaviour Scale (Part 1)
Mean Scores and Standard Deviations
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	172.3	171.6	171.2	163.2	162.7	160.4
SD	54.5	52.5	52.6	52.4	51.2	49.0

Maladaptive Behaviour

Comparison of overall mean scores for maladaptive behaviour, for controls, points to some differences over assessments T1-T6 as shown in Table 34. The mean score at baseline was 21.68 and at 18 months was ten points higher at 31.64. However, the

Friedman test does not reveal any significant differences (Chi-square 7.2800, D.F.5., P= .12). While the fluctuations in scores for the control group do appear large, these are fluctuations of mean. As the analysis is non-parametric - it is likely that a few high scores are pulling the means up - but do not show as significant in the analysis. The very high standard deviations, particularly at 6, 12 and 18 months, point to the wide variance.

Table 34

Maladaptive Behaviour
Mean Scores and Standard Deviations
Subjects - T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	21.7	27.1	27.6	31.6	19.5	17.2
SD	15.2	26.7	22.1	32.9	13.7	13.4

2) *Assessment of Community Living Skills*

Comparison of mean scores for controls on a sample of six direct observations of community living skills, as shown in Table 35, indicate some small changes over time. However, Friedman test reveals no significance for any of the conditions (see Table 36). For ease of comparison significance values are shown in Table 36 for each of the measures.

Table 35

Directly Observed Community Living Skills
Mean Scores and Standard Deviations (in parentheses)
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Pedestrian Crossing	2.9 (1.4)	3.0 (1.4)	3.2 (1.2)	2.4 (1.6)	3.1 (1.8)	4.0 (1.9)
Road Use	2.8 (1.4)	2.9 (1.5)	2.9 (1.5)	2.6 (1.6)	2.7 (1.8)	3.2 (1.7)
Restaurant Use	3.5 (0.8)	3.5 (0.9)	3.6 (0.9)	3.6 (1.1)	3.7 (0.9)	4.4 (0.7)
Shopping	3.5 (0.9)	3.5 (0.9)	3.8 (1.0)	3.6 (1.2)	4.0 (0.8)	4.6 (0.7)
Bus Use	3.0 (1.7)	3.4 (1.7)	3.4 (1.8)	3.2 (2.0)	3.7 (1.7)	3.2 (2.2)
Phone Use	2.6 (1.6)	2.3 (1.7)	2.3 (1.6)	2.3 (1.6)	3.2 (1.8)	2.5 (2.3)

Table 36

Friedman Chi-square Values and Significance Levels
Directly Observed Community Living Skills - Controls

	Chi-square	Degrees of Freedom	Significance
Pedestrian Crossing	2.0062	5	.57
Road Use	1.8176	5	.61
Restaurant Use	1.7550	5	.62
Shopping	1.9050	5	.59
Bus Use	2.5286	5	.47
Phone Use	2.9769	5	.39

3) *Confidence in Own Community Skills*

Overall mean scores are shown in Table 37, for controls, on the seven individual skills. As with the subjects group the small number of 'controls' at 30 months (T6) completing this measure - mean data were analysed for assessment T1 - T5 i.e. baseline to 24 months (see Table 16).

Little variation can be seen across time on this measure and the Friedman test shows no significance (chi-square 5.0500, D.F. 4, P = .28).

Table 37

Confidence in Own Community Skills
Mean Scores and Standard Deviations
Controls T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
mean	101.6	102.5	103.7	100.2	103.7
SD	15.7	17.0	16.3	20.8	19.5

4) *Staff Rating of Social Skills*

and

5) *Staff Rating of Interpersonal Skills*

Table 38 shows mean total scores for both of these measures for the control group.

Small changes in the mean scores on staff rating of social skills can be seen with a decrease from baseline (T1) to 30 months (T6) of approximately 6 points. Smaller changes are apparent on staff rating of interpersonal skills over the different assessments.

The Friedman test reveals no significance for staff rating of social skills (Chi-square 8.2976, D.F.5., P= .15) and for staff rating of interpersonal skills (Chi-square 4.1565, D.F.5., P=.53) for the control group.

Table 38

Staff Rating of Social Skills and Staff Rating of Interpersonal Skills
Mean Scores and Standard Deviations (in parentheses)
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Staff Rating of Social Skills	70.4 (26.0)	69.3 (25.6)	68.7 (23.7)	66.7 (24.7)	64.7 (28.1)	64.3 (23.2)
Staff Rating of Interpersonal Skills	77.0 (22.4)	76.2 (20.3)	77.5 (21.8)	74.3 (18.7)	74.9 (20.7)	76.2 (20.4)

6) *Self Rating of Interpersonal Skills*

Table 39 shows mean total scores for the control group over T1-T5 (baseline to 24 months). As with the subject group there were insufficient data to include the analysis at 30 months (T6). Mean scores vary a little with the highest score apparent at 24 months. The Friedman test reveals no significance (Chi-square 7.4533, D.F.4., P=.11).

Table 39

Self Rating of Interpersonal Skills
Mean Scores and Standard Deviations
Controls T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
mean	25.0	26.5	30.4	27.9	30.5
SD	8.0	7.3	5.8	8.6	7.1

Summary of Findings

The results from these six measures of competence and personal growth consistently reveal no significant changes for the control group over a 30 month period, while they remain in hospital. While they demonstrate no improvement in these areas the results also show that the control group do not deteriorate over the time period under investigation. Issues around 'disinvestment' in institutions, low morale and high turnover of staff facing uncertain futures has been referred to in some studies (c.f. Wing, 1989) as having potentially negative impact on aspects of residents lives while still in hospital. The experimental hypotheses is supported by the results demonstrating that people who remain in hospital show no significant change, over a period of time, in the area of skill acquisition and development.

Health and Well-Being

The experimental hypothesis was that there would be no change for health and well-being for people remaining in hospital.

Results from the 5 measures used to assess health and well-being are presented below.

1. *General Health Questionnaire (GHQ 30)*

The mean total scores for the General Health Questionnaire (GHQ) are presented in Table 40 for assessments T1-T4. As with the subject group there were insufficient numbers completing this measure at T5 and T6 and these data were therefore excluded from the analysis. Mean total scores are very low and make the interpretation of the data difficult.

The Friedman test reveals no significance (Chi-square .9414, D.F.3., P=.81).

Table 40

GHQ
Mean Scores and Standard Deviations
Controls T1-T4

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
mean	0.91	1.36	1.35	1.05
SD	2.84	1.86	1.62	1.94

2) *Zung Anxiety Scale*

and

3) *Zung Depression Scale*

Total scores on these measures were calculated and mean scores for assessments T1-T5 are presented in Table 41. The Friedman test reveals significance for Anxiety Scale (Chi-square 16.7231, D.F.4, P<.01) and Depressions Scales (Chi-square 19.9846, D.F.4, P<.001) for the control group with Wilcoxon showing differences for Depression Scale between baseline and 12 months (P<.001), baseline and 18 months (P<.001) between 6 and 12 months (P<.01) and 6 and 18 months (P<.001).

Scores on these scales decrease significantly for the control group from 12 months.

Table 41

Zung Anxiety and Zung Depression Scales
Mean Total Scores and Standard Deviations (in parentheses)
Controls T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Zung Anxiety Scale	8.2 (7.6)	7.1 (5.9)	4.8 (3.5)	4.3 (3.6)	2.4 (2.4)
Zung Depression Scale	13.6 (9.1)	12.4 (8.2)	7.8 (5.3)	5.2 (3.3)	2.3 (2.5)

4) *Eysenck Withers Personality Inventory*

Mean scores for Extroversion (E), Neuroticism (N) and Lie Score (L) are presented in Table 42.

No significant differences are revealed by the Friedman test over assessments T1-T4 for Extroversion (Chi-square 1.5643, D.F.3., P=.66); Neuroticism (Chi-square 4.8214, D.F.3., P=.18) and Lie Scores (Chi-square 1.2429, D.F.3., P=.74).

Table 42

Extroversion (E), Neurotisicm (N) and Lie Scores (L) - Eysenck Withers Personality Inventory
Mean Total Scores and Standard Deviations (in parentheses)
Controls T1-T4

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
Extroversion	14.4 (3.3)	14.7 (3.3)	13.0 (5.1)	14.1 (4.6)
Neuroticism	7.7 (4.6)	7.5 (4.9)	6.1 (3.5)	5.6 (3.9)
Lie	7.1 (2.5)	6.8 (2.1)	7.1 (2.3)	7.7 (2.9)

5) *Morale and Life Satisfaction*

Comparison of mean scores across assessment points are presented in Table 43. The mean score at baseline (T1) is 18.4 which then decreases over the next 4 assessments at 6, 12, 18 and 24 months. The mean score at 18 and 24 months, of 16.3 and 17.7 respectively, remains lower than baseline with an increase apparent at 30 months to a mean score of 21.9. The results imply a decrease in assessed morale and life satisfaction for the control group during the course of the study with an increase at month 30. The Friedman test shows significance but not at the more stringent .01 level (Chi-Square 10.2556, D.F.5., P<.05) with Wilcoxon showing differences between baseline and 12 months (P<.001) and 18 months (P<.01) and between 6 and 12 months (P<.01) and 6 and 18 months (P<.05). Differences were also apparent between 6, 12, 18 ,24 months and 30 months (P<.001)

While there are less participants involved with this measure at 24 and 30 months (see Table 16) there is no reason to expect that the groups are not representative. The numbers at 24 months (N=18) and 30 months (N=17) are almost identical, yet there is a significant difference in the scores between these points.

Table 43

Morale and Life Satisfaction
Mean Scores and Standard Deviations
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	18.4	17.6	15.9	16.3	17.7	21.9
SD	4.8	4.6	4.7	5.2	5.7	4.9

Summary of Findings

The results considered for the dimension of health and well-being yield a somewhat complex picture for those people who remain in hospital. No changes are found for the General Health Questionnaire and Eysenck Withers Personality Inventory - although as with the subject group there are some difficulties in drawing firm

conclusions from these data. The Zung Anxiety and Depression Scales demonstrate some changes showing a significant decrease for people who remain in hospital over time. Why people would show lower levels of anxiety or depression is unclear. However one explanation could be that participants are becoming familiar with the test over time and showing lower test anxiety. As referred to earlier, there is a question over the appropriateness of using these scales for the client group under investigation. Mean scores at all assessment points are low and not reflecting any psychological morbidity. Issues arising out of the use and interpretation of such instruments for people with learning disabilities are addressed further in the discussion.

The picture emerging from the morale and life satisfaction scale is of interest. People remaining in hospital could be adversely affected by seeing other residents leaving and, as a consequence, feel less satisfied with their own situation. Expectations may also have been raised with levels of dissatisfaction resulting from additional knowledge and information on alternatives to living in a hospital setting. Why levels of morale and satisfaction increase at month 30 is unclear and a subject for conjecture. One theory could be the improvement noted might be recording increased acquiescence effects on repeated presentation (c.f. Beswick, 1992). This does not mean that people remaining in hospital did not improve on such measures, but that estimates need to be made of the likely extent of such errors occurring in the data.

Results partly support the experimental hypothesis that people who remain in hospital do not experience any significant change in their health and well-being. However, the mixed results from some of the measures employed leave the question somewhat unanswered and raises a number of complexities in the assessment of this area for people with learning disabilities.

Quality of Care

The experimental hypothesis was that there would be no change in Quality of Care for people remaining in hospital.

Results from the three measures used to assess quality of care are presented below.

1) *Assessment of Living Units*

and

2) *Assessment of Lifestyles*

Comparison of mean scores presented in Table 44 show little change on these measures over time for the control group. The Friedman test reveals no significance for assessment of living units (Chi-square 5.8316, D.F.5., P= .21) or assessment of lifestyles (Chi-square 8.1088, D.F.5., P=.15).

Table 44

Assessment of Living Units and Lifestyles
Mean Total Scores and Standard Deviations (In Parentheses)
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Assessment of Living Units	24.2 (3.2)	25.6 (3.5)	26.1 (2.7)	26.1 (2.7)	26.3 (3.4)	27.3 (2.3)
Assessment of Lifestyles	36.4 (8.5)	36.5 (9.4)	27.8 (8.1)	36.0 (7.7)	35.3 (8.6)	36.8 (8.8)

3) *Personal Presentation*

The mean total scores of the Personal Presentation measure are presented in Table 45. No changes can be found over time.

Table 45

Personal Presentation
Mean Scores and Standard Deviations
Controls T1-T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Mean	15.7	15.7	15.5	15.4	15.2	15.3
SD	0.6	0.6	0.7	0.7	0.7	0.6

Summary of Findings

Results from these 'Quality of Care' measures support the experimental hypotheses that people remaining in hospital experience no change in their quality of care. The scales measuring living units and lifestyles appear stable over time which is what would be predicted for people who remain in the same setting. The measure of personal presentation shows little change with most people scoring the maximum or near maximum at all assessments.

111 COMPARISONS BETWEEN MOVERS AND STAYERS

The earlier part of this chapter examined separately the effects of relocation and the effects of remaining in hospital on people with a learning disability over a 30 month period. This section examines the differences between the groups on the different facets of quality of life under investigation. Comparisons between the two groups can establish that any gains made by the subjects are valid when contrasted with any or no change over the same period by the controls.

Competence and personal Growth

1) Adaptive Behaviour Scale

Table 46 shows the Mann Whitney Z scores and P values (2 tailed) for each assessment phase across T1 - T6. No significant differences were found between subjects and controls for overall adaptive behaviour at any of the individual time points. The mean scores point to the control group scoring marginally lower than subjects at all assessments but the analysis reveals no significant differences. Figure 1 provides graphical representation of the data for subject and control groups for ease of reference.

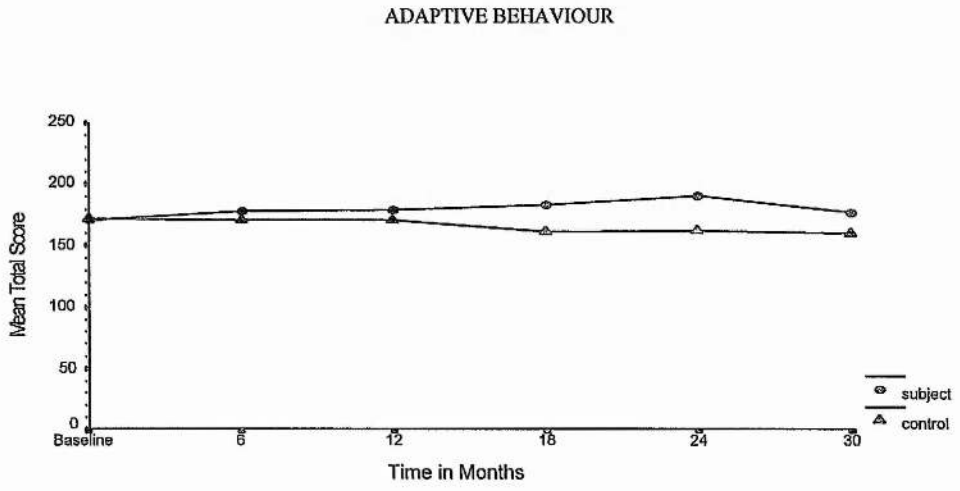


Figure 1: Mean total scores for Adaptive Behaviour (Part 1) - Subject and Control groups (T1 - T6)

Table 46

Adaptive Behaviour Scale
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Adaptive	χs	178.8	185.8	182.8	183.7	179.5	179.5
Behaviour	χc	172.3	171.6	171.2	163.2	162.7	160.4
Total	Z	-.683	-1.306	-.956	-1.488	-1.359	-1.344
	P	**.495**	**.191**	**.339**	**.137**	**.174**	**.179**
Numbers	χs	4.5	5.6	5.6	5.5	4.9	4.3
and	χc	5.5	5.8	5.7	5.8	5.4	4.4
Time	Z	-1.438	-.211	-.058	-.374	-.680	-.154
	P	**.150**	**.833**	**.954**	**.709**	**.496**	**.878**
Domestic	χs	8.0	11.3	11.5	11.1	11.2	10.1
Activity	χc	7.5	7.4	7.6	6.8	5.9	5.6
	Z	-.627	-3.533	-3.479	-3.376	-3.916	-2.787
	P	**.531**	**.000*** **	**.001** **	**.001** **	**.000*** **	**.005** **
Economic	χs	4.4	6.2	5.9	6.1	6.2	5.8
Activity	χc	4.3	4.7	4.2	4.1	3.8	3.6
	Z	-.108	-.977	-2.233	-1.690	-2.370	-1.580
	P	**.914**	**.329**	**.026***	**.091**	**.018***	**.114**
Maladaptive	χs	19.1	23.0	24.0	23.0	23.6	18.1
Behaviour	χc	21.7	27.1	27.6	31.6	19.5	17.2
	Z	-1.304	-.238	-.076	-703	-1.901	-.172
	P	**.192**	**.812**	**.940**	**.482**	**.057**	**.863**

χs mean score subjects
χc mean score controls
* .05 significance level
** .01 significance level
*** .001 significance level

An analysis of individual domains reveals significance for Domestic Activity at 6 months (T2), 12 months (T3), 18 months (T4), 24 months (T5) and 30 months (T6) in favour of the subjects. As the difference becomes evident at T2, following discharge, one possible explanation is that people living in the community are provided with more opportunity to engage in such tasks than are afforded to people living in hospital.

Some differences are also found in the area of Economic Activity but only at 12 months (T3) and 24 months (T5) and not at the more stringent .01 significance level. A comparison of mean scores between subjects and controls reveals a tendency for

subjects to have higher scores from 6 months (T2) onwards (i.e. following discharge). No differences were found in other domains. Figures 2 to 4 provide graphical representation of the data for subjects and control groups for these individual domains.

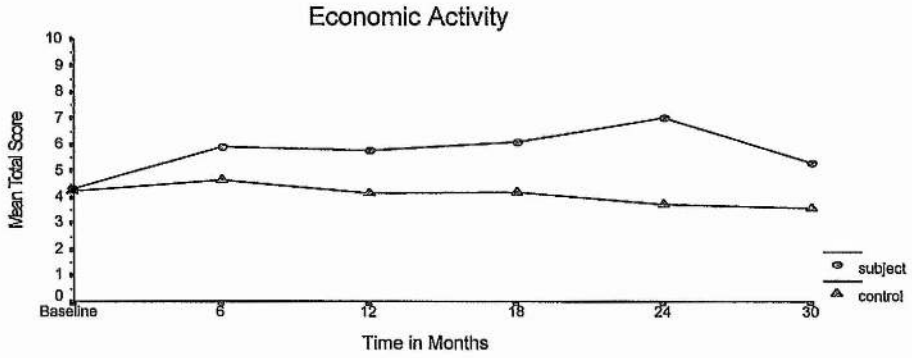


Figure 2: Mean total scores for Economic Activity - Subject and Control groups (T1 - T6)

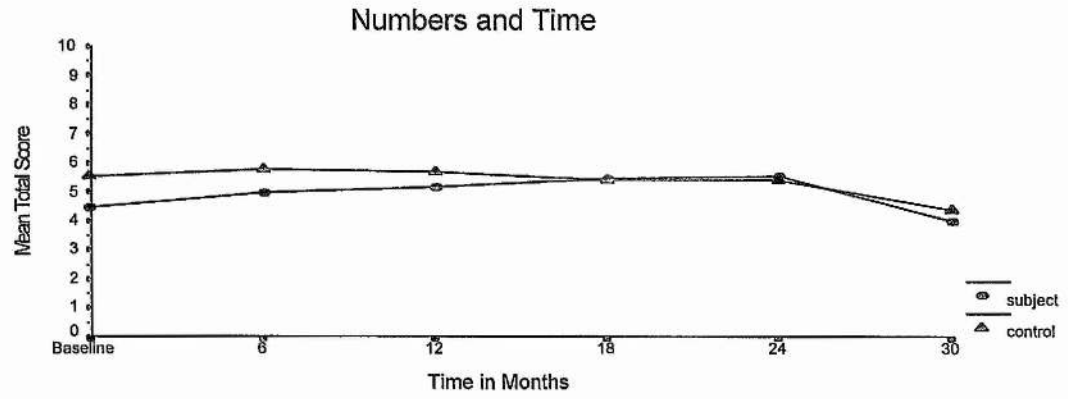


Figure 3: Mean total scores for Numbers and Time - Subject and Control Groups (T1 - T6)

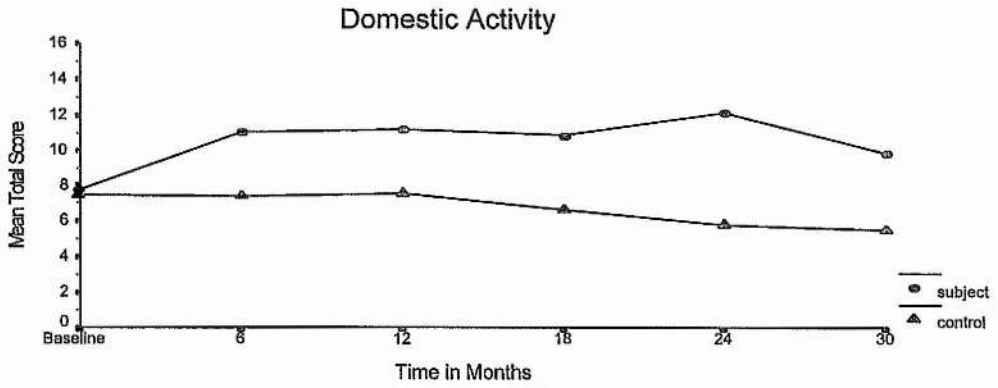


Figure 4: Mean total scores for Domestic Activity - Subject and Control groups (T1 - T6)

Comparing total maladaptive behaviour between the groups (see figure 5) points to a tendency to slightly higher scoring for the control group at baseline (T1), 12 (T2) and 18 (T3) months compared to the subject group. No statistically significant differences between the groups were found across T1 - T6 as shown in Table 46.

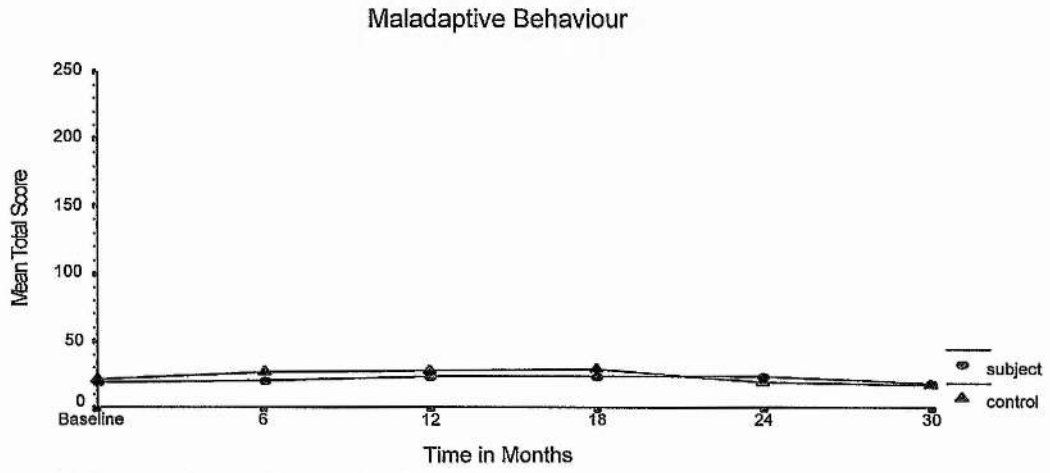


Figure 5: Mean total scores for Maladaptive Behaviour - Subject and Control groups (T1 - T6)

2) *Assessment of Community Living Skills*

Table 47 shows the Mann Whitney Z scores and P values for each assessment phase. Overall comparison of total scores showed no significant differences between subjects and controls at baseline, 6, 12, 18 and 24 months. A significant difference ($P < .01$) was found at 30 months in favour of the subject group.

Table 47

Directly Observed Community Living Skills (Total Differences between Subjects & Controls T1 - T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
χs	16	15	17	15	16	21
χc	18	18	19	16	16	6
Z	-1.598	-1.845	-.937	-.520	-.012	-2.766
P	**.110**	**.065**	**.349**	**.603**	**.990**	**.006****

However the number of controls taking part in this assessment at 30 months had decreased to 8 as shown earlier in Table 16. Interpretation of findings need to be considered in that context. Figure 6 provides graphical representation of the data.

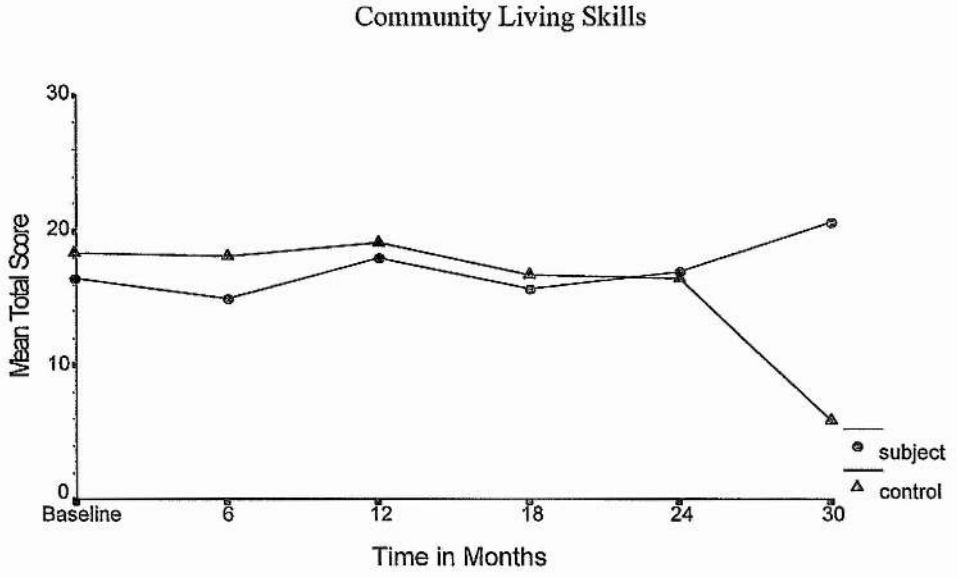


Figure 6: Assessment of Community Living Skills

In relation to the individual skills the subject group showed some modest gains in community living skills compared to the control group - possibly because they have more opportunity to engage in these activities. However, between group analyses reveals few significant differences as shown in Table 48.

Table 48

Directly Observed Community Living Skills
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Pedestrian Crossing	χs	2.9	3.3	3.7	3.6	3.8	4.1
	χc	2.9	3.0	3.2	2.4	3.1	4.0
	Z	-319	-1.006	-1.623	-2.785	-1.368	-.079
	P	**.750**	**.314**	**.105**	**.005****	**.171**	**-.937**
Road Use	χs	2.7	3.0	3.1	3.2	3.2	3.5
	χc	2.8	2.9	2.9	2.6	2.7	3.2
	Z	-.311	-.347	-.603	-1.354	-.787	-.210
	P	**.756**	**.729**	**.546**	**.176**	**.431**	**.834**
Restaurant Use	χs	3.4	3.7	3.7	3.8	3.9	4.1
	χc	3.5	3.5	3.6	3.6	3.7	4.4
	Z	-.417	-.769	-.593	-.533	-.666	-.730
	P	**.677**	**.442**	**.553**	**.595**	**.506**	**.466**
Shopping	χs	3.4	3.7	4.0	4.0	4.0	4.6
	χc	3.5	3.5	3.8	3.6	4.0	4.6
	Z	-.354	-.422	-.591	-.967	-.091	-.295
	P	**.723**	**.673**	**.554**	**.334**	**.927**	**.768**
Bus Use	χs	1.8	1.6	1.6	1.7	1.8	2.2
	χc	3.0	3.4	3.4	3.2	3.7	3.2
	Z	-2.276	-3.051	-2.943	-2.115	-2.286	-.819
	P	**.023***	**.002****	**.003****	**.034***	**.022***	**.413**
Phone Use	χs	2.2	2.3	2.1	2.4	1.9	1.9
	χc	2.6	2.3	2.3	2.3	3.2	2.5
	Z	-1.088	-.416	-.719	-.315	-1.644	-.492
	P	**.277**	**.677**	**.472**	**.753**	**.100**	**.623**

Only two areas point to a significant change. For pedestrian crossing a significant difference was found only at 18 months (T4). In comparing the mean scores for subjects and controls across T1 - T6 T4 points to a lower score for the control group rather than indicating any real improvement for the subject group at this point in time.

For bus use there is a statistically significant difference between the groups at baseline (T1), 6 (T2), 12 (T3), 18 (T4) and 24 (T5) months in favour of the control

group. The control group scored higher on this measure at baseline. The differences do not reflect any real change in relation to living in the hospital or in the community, rather it picks up an existing difference between the groups which is not evident at 30 months (T6).

On many of the measures there was no change for both groups. Visual analysis (c.f. Parsonson and Baer, 1986) suggests that such effects are not of much social or clinical significance when we look for a difference between the two groups (Figure 6). Overall, the very gradual change over time for both groups which occurred may represent changes which are taking place due to participation in the assessment process.

3) *Confidence in Own Community Skills*

Subjects and controls did not differ in their ratings of their confidence in own community skills over T1 - T5 as shown in Table 49.

Table 49

Confidence in Own Community Skills
Differences between Subjects and Controls T1-T5

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
χs	98.0	93.9	101.8	105.1	104.6
χc	101.6	102.5	103.7	100.2	103.7
Z	-.244	-.344	-.044	-.793	-.064
P	**.807**	**.731**	**.965**	**.428**	**.949**

It is of interest that, for people discharged into the community who have greater opportunity to engage in new skills, no real difference emerges when compared to people who remain in hospital with less opportunity available to them (see Figure 7).

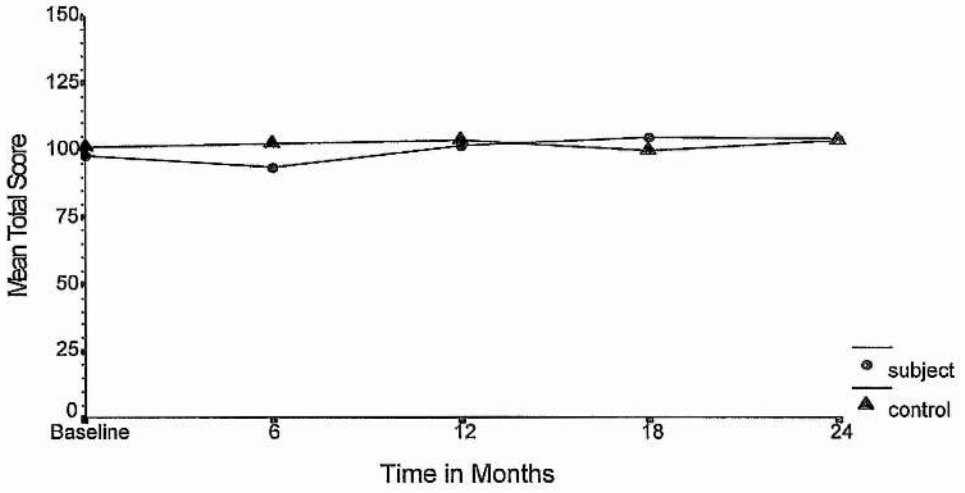


Figure 7: Mean total score for the Confidence in Own Community Skills - Subject and Control Groups (T1 - T5)_

4) *Staff Rating of Social Skills*

5) *Staff Rating of Interpersonal Skills*

Table 50 shows the Mann Whitney Z scores and P values over T1 - T6.

Table 50

Staff Rating of Social Skills and Interpersonal Skills
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
Staff	χs	69.6	72.8	70.2	72.2	69.1	69.4
Rating of	χc	70.4	69.3	68.7	66.7	64.7	64.3
Social	Z	-.154	-.738	-.682	-1.198	-.342	-1.004
Skills	**P**	**.878**	**.461**	**.495**	**.231**	**.733**	**.316**
Staff	χs	75.5	80.6	79.1	81.7	78.6	80.7
Rating of	χc	77.0	76.2	77.5	74.3	74.9	76.2
Interpersonal	Z	-.231	-1.766	-.411	-1.864	-.711	-.967
Skills	**P**	**.817**	**.077**	**.681**	**.062**	**.477**	**.334**

No differences are revealed between subjects and controls at any assessment. Mean scores indicate a tendency for subjects to score marginally higher from 6 months (T2) compared to controls (Figures 8 & 9).

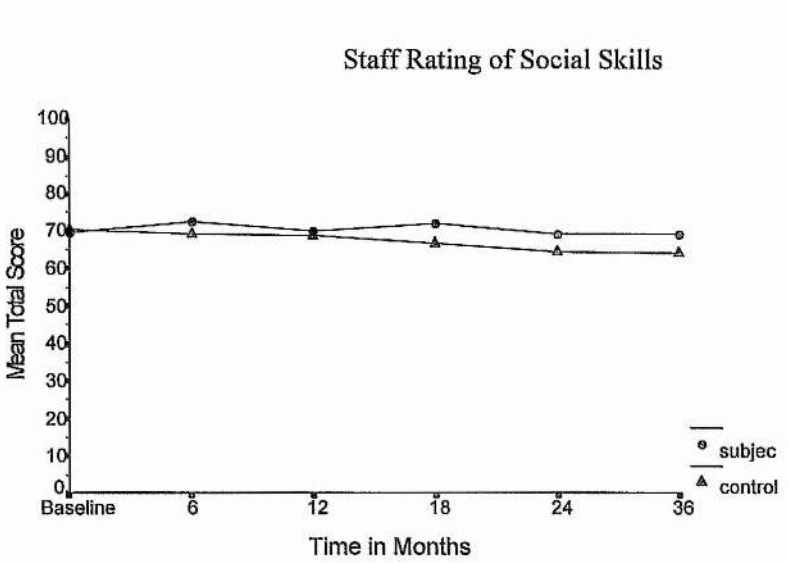


Figure 8: Mean total scores for Staff Rating of Social Skills - Subject and Control groups (T1 - T6)

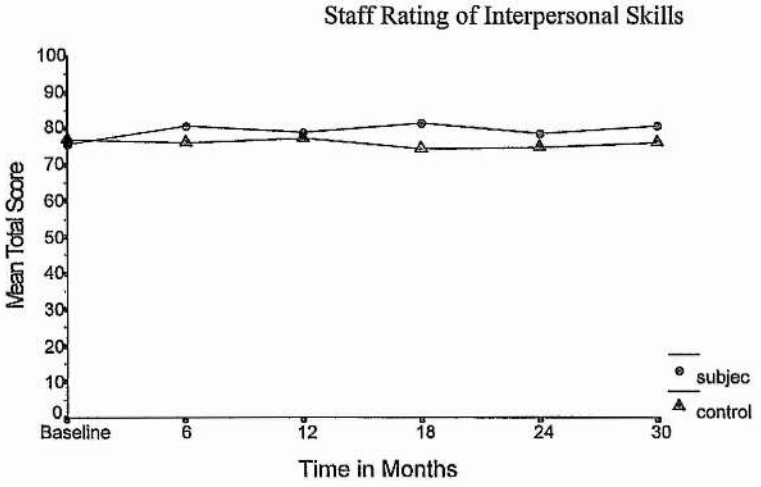


Figure 9: Mean total scores on the Fife Interpersonal Questionnaire for the subject and control groups.

6) *Self-Rating of Interpersonal Skills*

Mann-Whitney values and probability levels are shown in Table 51 for T1 - T5.

Table 51

Self Rating of Interpersonal Skills
Differences between Subjects and Controls T1 - T5

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Self	χs	26.2	29.2	33.4	32.5	33.1
Rating of	χc	25.0	26.5	30.4	27.9	30.5
Interpersonal	Z	-.713	-1.990	-2.569	-1.979	-1.165
Skills	**P**	**.476**	**.047**	**.010****	**.048***	**.244**

A statistically significant difference is found only at 12 months (T3) (P <.01) and at 18 months (T4) (P< .05) in favour of the subject group. Mean scores for both groups show a tendency to increase from 6 months(T2) (Figure 10).

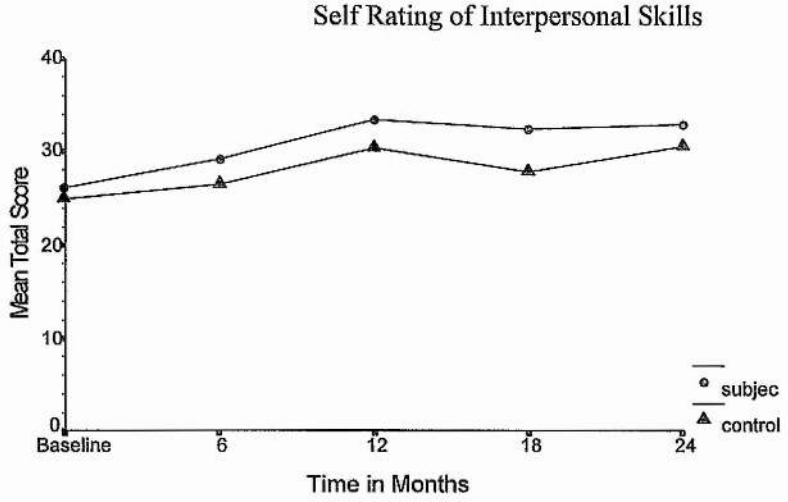


Figure 10: Mean total scores for Self Rating of Interpersonal Skills - Subject and Control Groups (T1 - T5)

Summary of Findings

The results from the six measures used in the present study reflecting the general quality of life indicator of competence and personal growth point to few real differences for people leaving hospital relative to those who remain. On the adaptive behaviour scale, while no overall differences emerge an analysis of individual domains reveals significance in favour of the subjects for Domestic Activity. The difference becomes apparent at 6 months immediately following discharge. The subjects maintain the improvement over time although there is no evidence of continued development. In the area of Economic Activity the subject group showed a significant improvement from 6 months onwards but when compared to the control group the differences are apparent only at 12 months (T3) and 24 months(T5) pointing to some variability within the subject groups over time.

While the subject group showed a statistically significant improvement on Numbers and Time from 6 months no difference was evident when comparing subjects with controls.

No differences between the groups are apparent in the area of maladaptive behaviour. However, the subject group showed a significant increase at 12 (T3) and 24 months (T5) and while some increases were noted for the control group they do not reach statistical significance. It would seem reasonable to conclude that this measure is sensitive to variability in behaviour over time and that there may be differing expectations in the community accounting, in part, for the significant change within the subject group. There is no evidence to support the view that 'more difficult' people remain in hospital.

However, in general, the mean scores on maladaptive behaviour for both groups remain low - although there is some difficulty in interpreting the significance of overall scores - as some behaviour falls into the range of 'normal' expectations (Nihira et al, 1975). More detailed analysis of the sub-domains for both groups was not considered appropriate given the overall low level of scoring. Reliability of the maladaptive behaviour of the ABS is quoted as .57 (Nihira et al, 1975) so interpretation of results require to be considered in this context.

On a sample of community living skills assessed by direct observation a difference in favour of the subjects was found only on pedestrian crossing and only at T4. It would seem that both groups show some small gains in these areas which can be partly attributed to their taking part in the assessment process.

No differences between the group emerged on confidence in own community skills and staff ratings of social and interpersonal skills. An occasional significant result is found such as on self rating of interpersonal skills at T3 which could be an artefact of the numbers in the different groups reducing over time and the likelihood of finding a significant result in such analysis. No conclusion can be drawn from such findings.

Overall any differences between the groups tend to be in favour of the subjects with most changes occurring following discharge and remaining somewhat stable, if not declining a little thereafter.

Health and Well Being

1) *General Health Questionnaire*

Table 52 shows Mann-Whitney Z scores and P values over T1 - T4. As explained earlier the low numbers of subjects and controls involved at T5 and T6 resulted in these data being excluded from the analyses.

Table 52

General Health Questionnaire
Differences between Subjects and Controls T1 - T4

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
General	χs	1.34	1.10	0.44	1.84
Health	χc	0.91	1.36	1.35	1.05
Questionnaire	Z	-.243	-1.155	-1.134	-1.032
	P	.808	.248	.257	.302

No significant differences were found between subjects and controls on T1 - T4

2) Zung Anxiety Scale

3) Zung Depression Scale

The analyses of scores from the Zung Anxiety Scale reveals no significant differences between the subject and control groups at each assessment time as shown in Table 53. The Zung Depression Scale reveals a significant difference between the groups at 6 months (T2) only. Both groups show a decline in scoring over T1 - T5 (see Figures 11 & 12).

Table 53

Zung Anxiety and Depression Scales
Differences between Subjects and Controls T1 - T5

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Zung	χs	7.9	6.0	6.7	4.8	4.0
Anxiety	χc	8.2	7.1	4.8	4.3	2.4
Scale	Z	-.102	-1.241	- .229	-.040	-1.396
	P	**.919**	**.215**	**.819**	**.968**	**.163**
Zung	χs	12.2	6.4	7.8	4.5	4.2
Depression	χc	13.6	12.4	7.8	5.2	2.3
Scale	Z	-1.162	-3.126	-.818	-1.699	-.743
	P	**.253**	**.002****	**.414**	**.089**	**.458**

Zung Anxiety Scale

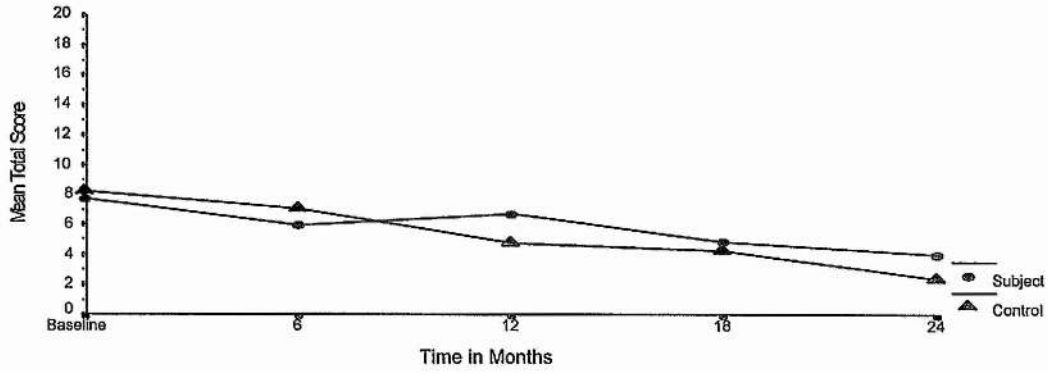


Figure 11 : Mean scores for Zung Anxiety scale - Subject and Control groups (T1-T5)

Zung Depression Scale

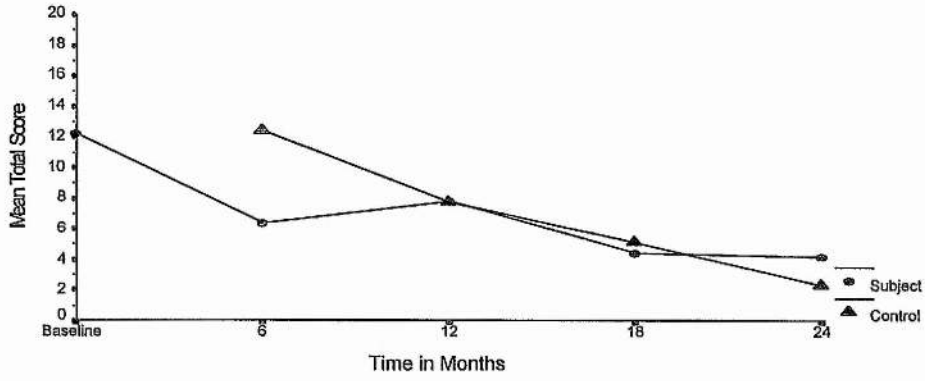


Figure 12 : Mean scores for Zung Depression scale - Subject and Control groups (T1-T5)

4) *Eysenck Withers Personality Inventory*

Table 54 shows the results of the between group analysis for the Eysenck Withers for extroversion, neuroticism and lie score.

No significant differences were found for T1 - T4 at any assessment time. The mean scores for both groups show little change over time as shown in Figures 13 and 14.

Extroversion and lie scores are within the range found by Eysenck (1967) for a group of people with a moderate learning disability while the neuroticism scores are lower. The lie score is higher than one would expect from a non learning disabled population and Eysenck explains this as a possibility that institutionalised patients wish to please the tester.

Table 54

Eysenck Withers Personality Inventory
Mann Whitney Probability Values Subjects and Controls T1 - T4

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)
Extroversion	χs	14.6	14.3	14.6	15.1
	χc	14.4	14.7	13.0	14.1
	Z	-.355	-.161	-.974	-.363
	P	**.722**	**.872**	**.330**	**.715**
Neuroticism	χs	5.8	5.6	5.1	5.9
	χc	7.7	7.5	6.1	5.6
	Z	-1.431	-1.359	-1.370	-.077
	P	**.153**	**.174**	**.171**	**.939**
Lie Score	χs	6.0	6.8	7.8	6.8
	χc	7.1	6.8	7.1	7.7
	Z	1.212	-.097	-1.030	-.957
	P	**.226**	**.923**	**.303**	**.339**

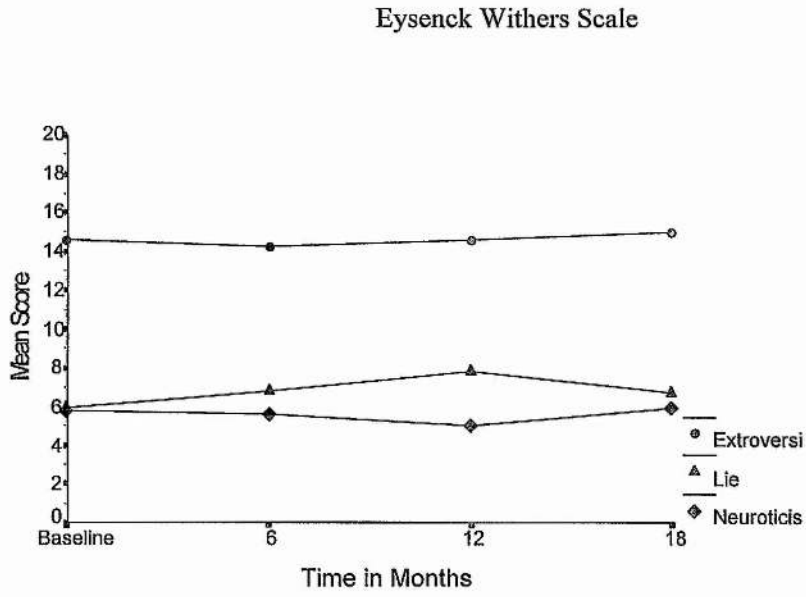


Figure 13 : Mean scores for Eysenck-Withers scale - Subject group (T1-T5)

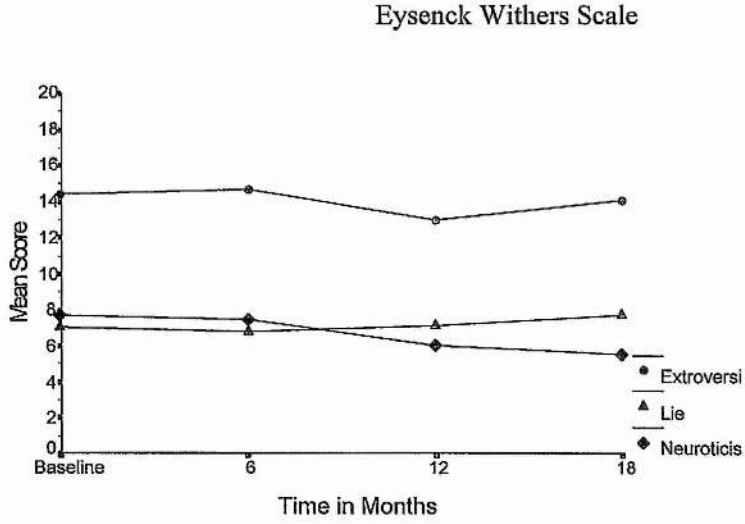


Figure 14: Mean scores for Eysenck-Withers scale - Control group (T1-T5)

5) *Morale and Life Satisfaction*

On the measure of morale and life satisfaction significant differences between subjects and control groups are found at 6 (T2), 12 (T3), 18 (T4) and 24 (T5) months ($P < .01$) in favour of the subject group as shown in Table 55.

Table 55

Morale and Life Satisfaction
Differences between Subjects and Controls T1 - T6

	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	30 months (T6)
χs	16.9	23.5	23.3	22.0	21.7	22.0
χc	18.4	17.6	15.9	16.3	17.7	21.9
Z	-1.421	-5.462	-5.619	-4.106	-2.725	-.878
P	**.155**	**.000*** **	**.000*** **	**.000*** **	**.006** **	**.427**

While both groups have reasonably similar scores at baseline, the improvement for subjects, relative to the control group, is apparent at first follow up and maintained thereafter. It is of interest that subject and control groups have similar scoring at 30 months with no significant difference between the groups (See figure 15). The measure no longer discriminates between the two groups at this stage with the control group mean score increasing to that of the mean score for the subject group. The smaller number of people participating in this assessment at 30 months may be a contributing factor to this outcome.

Morale and Life Satisfaction

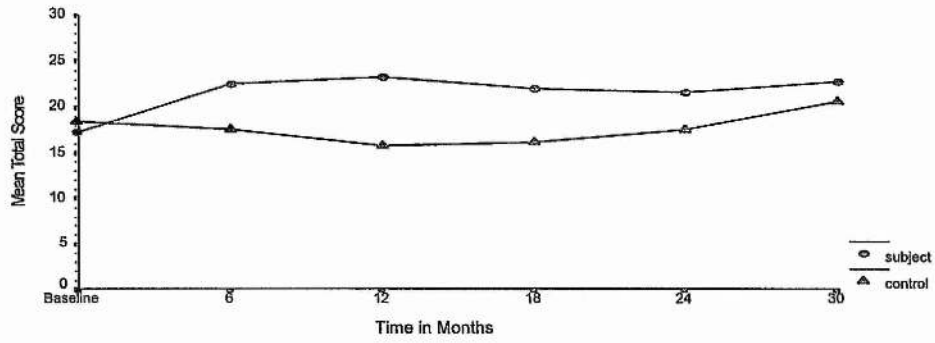


Figure 15: Mean total scores for Morale and Life Satisfaction - Subject and Control groups (T1 - T6)

Summary of Findings

Overall the measures used in the present study to assess Health and Well Being provide mixed results in relation to identifying any differences between subjects and controls. Both groups show a decline in anxiety and depression as assessed by the Zung scales over T1 - T5. No change is found for the General Health Questionnaire but the scores for both groups are very low, well below the threshold for a

significant clinical disturbance. The measure of morale and life satisfaction appears to be more successful at discriminating between people who are living in hospital compared to those who have left.

The issue of how best to assess health and well-being from a person's own point of view remains a challenge for studies like this (cf Hatton, 1998). There may be subtle changes that are being picked up by the measures used here which result in the variability shown between and within groups over time. This area will be addressed further in the discussion.

Quality of Care

Assessment of Living Units

Assessment of Individual Lifestyles

The measures developed specifically for the present study to assess quality of living units and individual lifestyles appear to be most effective at discriminating between subject and control groups. Tables 56 and 57 present the results over T1 - T6.

Table 56

Assessment of Living Units
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	36 months (T6)
Assessment	χs	23.3	37.6	38.0	38.5	37.8	38.3
of	χc	24.2	25.6	26.1	26.1	26.3	27.3
Living	Z	-.463	-8.073	-8.038	-8.010	-6.644	-5.458
Units	**P**	**.643**	**.000*** **	**.000*** **	**.000*** **	**.000*** **	**.000*** **

Table 57

Assessment of Individual Lifestyles
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	36 months (T6)
Assessment	χs	39.7	52.5	53.7	52.7	53.4	49.7
of	χc	36.4	36.5	27.8	36.0	35.3	36.8
Individual	Z	-2.162	-7.120	-7.524	-6.568	-6.355	-4.267
Lifestyles	**P**	**.031**	**.000*** **	**.000*** **	**.000*** **	**.000*** **	**.000*** **

A significant difference between the group (P < .001) is apparent on both measures from 6 months (T2) onwards, that is following discharge of subjects from hospital to community settings. While there is no progressive improvement for the subject group from 6 months (T2) - (see Figures 16 and 17) - one should question what people should be aiming to achieve in these areas to maximise their quality of life. A move from hospital to a community setting, in itself, appears sufficient to generate the improvements shown.

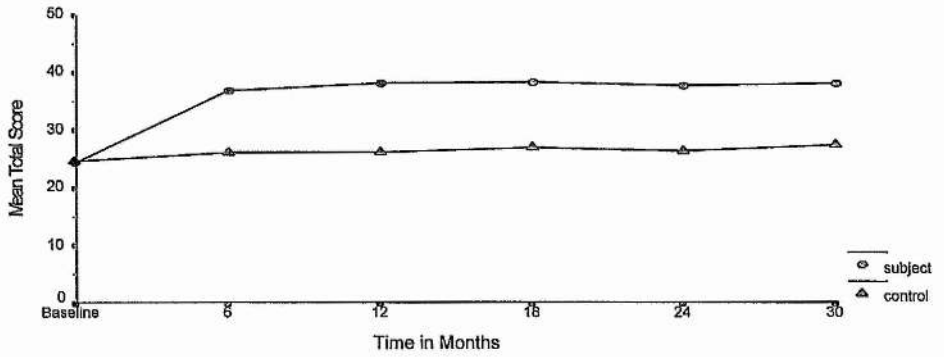


Figure 16 : Mean scores for Assessment of Living Units - Subject and Control groups (T1-T6)

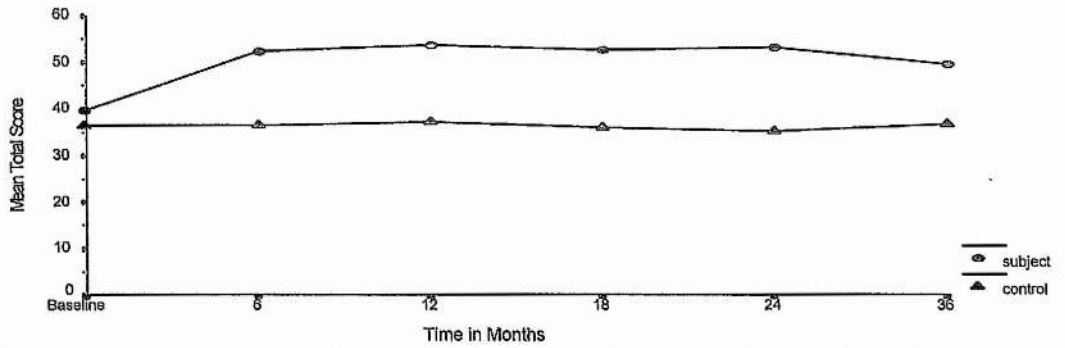


Figure 17 : Mean total scores for Assessment of Individual Lifestyles - Subject and Control groups

Personal Presentation

The analysis of data derived from the measure of personal presentation points to a tendency towards significance at T2, T3, T4, T5 & T6. Table 57 displays Mann Whitney scores and P values.

Table 58

Personal Presentation
Differences between Subjects and Controls T1 - T6

		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)	36 months (T6)
Personal	χs	15.7	16.0	15.8	15.7	15.4	15.8
Presentation	χc	15.7	15.7	15.5	15.4	15.2	15.3
	Z	-.236	-2.024	-2.114	-2.290	-2.125	-1.983
	P	**.813**	**.043***	**.034***	**.022***	**.034***	**.047***

While mean scores differ only slightly (see figure 18) there is a difference between subjects and controls from first follow up onwards. However as scores are, in the main, near the maximum the difference does not necessarily indicate big changes. The differences do not reach the more stringent .01 significance level.

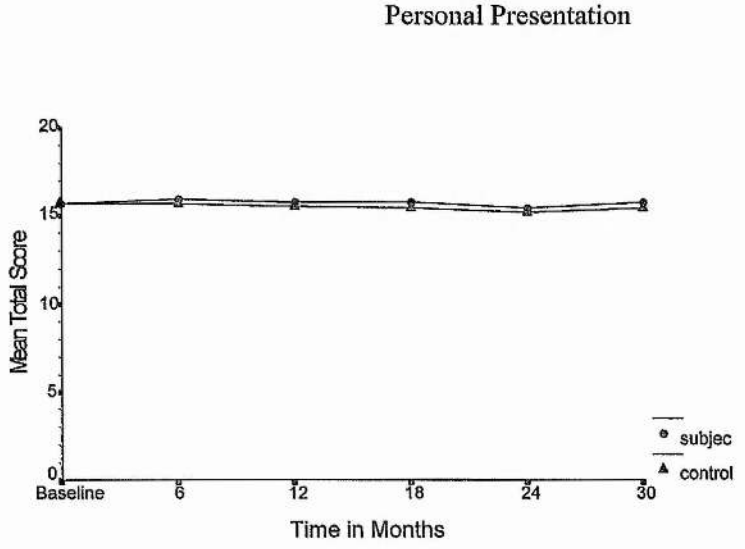


Figure 18: Mean total scores for Personal Presentation - subject and control groups (T1 - T6)

In summary, some general conclusions can be drawn from the results reported in this chapter which are considered further in the discussion.

People who leave hospital:

- show little change in their competence and abilities and develop few new skills once they have settled in the community;
- show some increase in maladaptive behaviour;
- express a higher degree of satisfaction with their life in the community and services they receive;
- exhibit no increase in relation to measures of anxiety and depression;
- experience a higher quality of living environment and
- experience a more enriched lifestyle.

People who remain in hospital:

- show no change in their competence, abilities and skills;
- show no change in their maladaptive behaviour;
- express some changes, both positive and negative, in relation to their degree of satisfaction with their life over time;
- show, if anything, a decrease in self assessment of anxiety and depression;
- experience no change in their quality of environment and
- experience no change in their quality of lifestyle.

Comparison between 'movers' and 'stayers' point to:

- few differences between the groups in relation to their competence, abilities and skills over time. Differences that do emerge tend to occur at the first follow up in favour of the subjects who have moved to community settings and remain stable or decline a little thereafter;
- no differences between the groups on the measure of maladaptive behaviour although some within group variability was apparent;
- almost no differences between the groups on measures of general health, anxiety and depression;

- a significant difference between the groups in relation to their degree of expressed satisfaction with their life which is apparent at the first follow up when people have moved from hospital to the community settings and maintained thereafter up until 30 months; and
- a significant difference between the groups in quality of living environments and lifestyles once subjects have moved from hospital. Subjects show a significant improvement compared to the control group on these measures from first follow up.

Discussion

Overall Findings

The study involved 100 people with learning disabilities for up to a 30 month period in their lives and was concerned with two main issues - the effects on people of moving from hospital to the community and the effects on those remaining in hospital. This latter issue is often glossed over, particularly with respect to assessing what happens to people over a period of time with immediate pre and post data more readily available.

The results obtained from this study illustrate the multidimensional nature of quality of life. Each of the outcome measures casts a slightly different light on the complex picture of the effects of deinstitutionalisation on the quality of life of its recipients, with some of the experimental hypotheses supported and some rejected.

Overall it is clear that no advantage is gained by remaining in an institution although no significant deterioration occurs contrary to some findings (e.g. Beswick, 1992). Whatever differences there are between subject and control groups are almost always in favour of the subjects. This supports the general conclusion of most commentators such as Larson and Lakin (1989) and Brook and Bowler (1992). However the gains are generally modest in scale and are to be found soon after relocation with no major changes and sometimes a small decline over time thereafter. This supports the view that the process of moving to a community based residence may result in some initial changes but will not, in itself, bring about the major long term changes which many feel ought to be happening for people who have spent many years in institutions.

As Lowe et al (1993) point out "no study has shown accelerated improvement over time arising from community placement" (P4).

The overall findings need to be considered in the context of some of the methodological constraints.

Firstly, the study design was not an exact matched group design and, while individuals were matched on a number of 'key' variables, it was not possible to take account of all the individual characteristics that may or may not have contributed to the outcome (given that many are still unknown!). However, this is an issue for most areas of applied research and the matched design employed in this study is similar to many others in the field (e.g. Beswick, 1992; Emerson et al, 1992; Felce et al, 1986; Hemming et al, 1981; Mansell and Beasley, 1993). Prematched control group design provides, potentially, more robust data than straight comparative designs and appears to be most often described as the "best" alternative quasi-experimental design. However Beswick (1992) points out that possible sources of error in such studies are selection interactions (i.e. differences in group composition which may be undetected by the matching process, but may be important in effecting client progress) and statistical regression (i.e. tendency for extreme scores to be less extreme on reassessment).

The inclusion of a repeated measures within groups design overcame some of the potential problems with the above. The longitudinal nature of the study reflected the concept that adjustment is a process.

Secondly, outwith the control of the researcher, was the problem associated with the fall off in numbers with a much smaller sample size at 30 months. While the numbers in the study were higher than most other studies in the U.K. (cf Emerson and Hatton, 1994) it is still a relatively small number given the heterogenity of the total group of people who are being moved out of institutions. Because of the reduced sample size at 24 and 30 months it was considered too small to allow meaningful analysis of whether there are particular person variables which are associated with successful placement.

Thirdly, the selection of measures attempted to address some key aspects involved in the complex area of quality of life assessment. The study does not purport to have measured "quality of life" in its entirety and a number of areas relevant to quality of life, such as community participation and material well-being, were not included. The instruments devised seem to have face validity but there is still a real need for

service providers, clients and advocates to agree on the criteria by which services may be judged (e.g. Baer, 1988).

Finally, the reliability of some of the measures were low, particularly relating to measures seeking clients' own views.

Not withstanding the above, the findings of the present study make a significant contribution to the overall picture of the lives of people with learning disabilities in hospital and community settings and contribute to the growing literature in the field which is aimed at influencing policy makers and services providers.

The specific implications of the findings and how they compare with other studies are discussed below in relation to the three main areas under investigation: Competence and Personal Growth; Health and Well-Being and Quality of Care. While comparisons with other studies are made, it is recognised that methods of data collection, along with the length of time subjects have been in the community, vary between studies. However, there is still merit in considering other findings having taken note of these issues.

Competence and Personal Growth

Overall there was no improvement for people who left hospital, nor was there any real deterioration for people who remained in hospital on measures of competence and personal growth. This area incorporated a range of measures aiming to assess skills and abilities in a number of ways. While measures of adaptive and maladaptive behaviour are commonplace in research on deinstitutionalisation, specific measures involving social and interpersonal skills per se and direct observations of specific skills are less often cited in the literature. Of particular importance was the attempt to assess participants' own perceptions of their skills thus addressing both the subjective and objective components of evaluation of this facet of quality of life (e.g. Felce and Perry, 1995a).

While some initial benefits were found for people who left hospital, relative to those who remained, these tended to be confined to two or three key specific areas such as

use of money, domestic activity and shopping. The groups differed at the outset only in relation to one measure, bus use, where controls were found to have higher level of skill. This difference was maintained up until 24 months with both groups showing little change over time. Further development did not take place on most measures over time so the assessed improvement may not represent increased competencies but rather an opportunity to use skills already in the repertoire (cf O'Neill et al, 1985). No deterioration was found for people remaining in hospital a finding which does not lend support to the view that some loss of skill occurs over time (e.g. Beswick, 1992). The Adaptive Behaviour Scale covers a wide range of behavioural domains but is not sensitive to relatively small changes in behaviour. The norms are based on American inpatient populations and, while used widely in the U.K. for clinical and research purposes, the use of U.K. norms might have been more appropriate. While considered a reliable instrument, Perry and Felce (1994) found domain reliabilities ranged from 58% to 89% and urged caution when interpreting results. Maladaptive behaviour increased for people living in the community but did not change as a consequence of living in hospital. Maladaptive behaviour would seem to persist and increase in community settings and as such can not solely be attributed to institutional living. Levels of maladaptive behaviour, overall, were low although with quite considerable individual variation.

When interpretation of small scale change is important, assessment by staff report should be complemented by approaches based on client assessment and observation (cf Perry and Felce, 1996). The remaining measures employed to assess the area of skill development aimed to do this.

The direct assessment of community skills potentially picks up smaller gains in specific areas and the skills were so selected as to cover a range of everyday situations people encounter in community settings. While some improvement on the range of skills assessed are apparent for people moving to the community, the findings also point to improvements in one area (shopping) occurring after some time (i.e. after 12 months). This may be as a result of increased opportunities over a period of time or be indicative of the time it may take for certain new skills to be acquired. There was little to differentiate between the two groups on these measures.

The assessment of social and interpersonal skills is an important one and 'in-house' measures were used in the present study including a self assessment measure. Further refinement of these questionnaires could give consideration to possible assigning values or weightings, dependent on how relevant/important a particular skill/behaviour is considered to be. Despite these shortcomings the data generated from these measures allows for some consideration of the area and the effect on people of living in institutional or community settings. The relevance of this area is in relation to the identification of skills and behaviour that will facilitate people in their interactions with each other and to enable them to participate meaningfully in their community. It is clear that moving people to the community, per se does not in itself lead to an improvement in their social and interpersonal skills. This area has not been addressed specifically in most of the studies to date.

In comparing these results with other studies the most directly comparable findings relate to adaptive and maladaptive behaviour.

Comparative studies of hospital and community settings have reported some mixed findings in this area. With regards to adaptive behaviour, some have reported significant increases for people moving to the community (e.g. Knapp et al, 1992; Lowe et al, 1993; Maisto and Hughes, 1995) while others reported no change (e.g. Beswick, 1992; Lister, Brook and Bowler, 1995). There is evidence from a number of studies of a 'plateau' effect (e.g. Cambridge et al, 1994; Lowe et al, 1993) that is, after any short-term gains in adaptive behaviour upon resettlement have occurred, service users are unlikely to continue to gain significant new skills in the long term. Within this general plateau effect, it is possible that service users with low abilities continue to gain new skills while more able service users remain static or lose some skills (Felce and Perry, 1996; Lynch, Kellow and Willson, 1997).

The reasons for some of these reported differences between studies remains unclear. The range of methodological approaches used by different investigators may contribute to this (cf Lynch, Kellow and Willson, 1997). Resident characteristics is one explanation (e.g. Perry and Felce, 1994). Different models of service provision or even similar models of service provision could account for some of the variation.

There is some evidence that specific assistance and direction from staff can increase individual competencies (e.g. Felce and Perry, 1995b; Mansell, 1995) and this type of staff behaviour is likely to be present in some settings and not in others.

Only a few studies (e.g. Knapp et al, 1992; Cambridge et al, 1994; Lowe et al, 1993) report findings more than one year after discharge to the community. While it may take people with a learning disability a relatively long time to learn new skills, the present study, with a 30 month follow up, still failed to find any overall significant changes.

Findings from studies relating to maladaptive behaviour are also rather mixed. A number of studies have found no change or a decrease in maladaptive or challenging behaviour for people going from hospital to community settings (e.g. Bratt and Johnson, 1988; Donnelly et al, 1994; Booth et al, 1990; Lister, Brook and Bowler, 1995). Other studies have found an increase (e.g. Felce et al, 1994) in maladaptive behaviour.

Hatton and Emerson (1996) point out that the differences in some of the findings are related to how researchers measured the behaviour. Studies using rating scales, such as the ABS, with their focus on infrequent but inappropriate or challenging behaviours report, in the main find no difference or an increase in community settings in challenging behaviour across service models. Studies using observational schedules, with their focus on high duration but minor challenging behaviours, report no difference in challenging behaviour across service models or a decrease in challenging behaviour in community settings. The present study, employing the ABS, found an increase in maladaptive behaviour in the community. Emerson and Hatton, (1994) pointed out that the generally enriched material environment and increased demands made upon service users in community settings is likely to set the occasion for some forms of more serious challenging behaviours, while reducing minor, self stimulating challenging behaviours such as stereotypic behaviour. The increase in maladaptive behaviour found in the present study may be associated with such a change, although another explanation may be that some behaviours in the community are considered maladaptive - whereas in the hospital setting are not labelled as such.

Health and Well-Being

The findings from the self-report measures of health and well-being are, in the main, difficult to interpret. Apart from the measure of morale and life satisfaction, the application of assessments such as the General Health Questionnaire and Zung Anxiety and Depression Scales in the present study is questionable with a learning disabled population despite some reports to the contrary (cf Prout and Schaeffer 1985; Lindsay and Michie, 1988). Even the use of Eysenck-Withers Personality Inventory, designed for people with a moderate and mild learning disability, appears unreliable in the present study. Despite the inconclusive results, this area is one of great importance and the present study attempted to tap into the subjective assessment of the participants' well-being rather than rely solely on second or third hand information. Few studies have incorporated an assessment of mental health although some attention has been given to the area of physical health but mainly reporting on the co-morbidity of specific conditions such as epilepsy (e.g. Moss and Turner, 1995). Hatton and Emerson (1996) note that more research is required concerning the health of people with learning disabilities in different residential settings, particularly in relation to Health of the Nation Key Areas (Department of Health, 1995). Hayden and De Paepe (1991) have pointed out that paying attention to the health-neglected needs of people with learning disabilities, is a challenge for community-based services.

The area of mental health has received less attention than physical health with only 6 out of 70 studies on living settings in the U.K. reporting any findings concerning the mental health of people with learning disabilities (e.g. Hatton and Emerson, 1996) despite evidence to suggest prevalence rates of psychiatric disorders of between 9% to 41% (Bouras and Drummond, 1992; Inverson and Fox, 1989; Reiss, 1994). However there appears to be a relationship between the presence of a psychiatric disorder and the level of ability of the person (Jacobson, 1990). In people with mild, and to some extent, with moderate learning disabilities, the symptoms of psychiatric disorders are essentially the same as those seen in people without a learning disability (Bouras and Drummond, 1992). In contrast, psychiatric and emotional problems in people with severe and profound learning disabilities tend to

be highly individualistic (Easton and Menolaxino, 1982) and might present as behavioural problems (Reiss, 1985), thus underestimating the prevalence of psychiatric disorders for this client group.
Of the few studies available, the results are not by any means conclusive.

Two studies (Donnelly et al, 1994; Knapp et al, 1992) reported findings concerning the short term impact of moving from hospitals to community settings on the mental health of people with learning disabilities, reporting improvements in levels of depression one year after moving. This was assessed by asking staff to rate items on a questionnaire and, for some people with learning disabilities, getting them to rate their own mood.

Another study (Cambridge et al, 1994) found no changes in depression or psychological functioning after people had moved from hospital to community settings. There is some suggestion that psychological well-being is lower in people with learning disabilities (Thomson and Schaeffer, 1988) and that there is an association between depressed mood and personal skills (Kaman and Reiss, 1987).

In a separate study concerned with the assessment of anxiety for people with learning disabilities (rather than the effects of different living situations) Lindsay and Michie, (1988) found some problems with the use of self rating scales and suggested that a simple yes/no format as opposed to a categorisation on the basis of degree of anxiety was more appropriate and reliable. However Prout and Schaefer (1985) concluded that persons with mild learning disabilities were able to make valid and reliable responses to unmodified self-report measures such as the Zung Depression Scale.

The studies available, and the methodological problems involved in assessing mental illness and psychological states in people with learning disabilities, mean that estimates of the prevalence of mental health problems and the effects of changes in living circumstances for most users are currently unavailable (e.g. Moss, 1995; Reiss, 1994). Most of the studies have relied on information from other parties (e.g. staff, relatives etc.) rather than assess psychological states from the individual's perspective.

The present study's attempt to use a range of measures to assess psychological subjective states of people with learning disabilities met with very limited success. However, the assessment of morale and life satisfaction by directly seeking individual views appeared more effective in discriminating changes between hospital and community settings. This assessment was designed for use with people with a learning disability and attempts to ascertain how satisfied people feel about their life and living situation. These findings support evidence from other studies (e.g. Beswick, 1992; Donnelly et al, 1994). Some variability within subject and control groups was apparent over time. The highest assessed satisfaction for subjects was found immediately on discharge and at 12 months. Beswick (1992) suggests that there is a typical pattern of change in subjects' opinions which occurs in the first two or three years after relocation.

Up to a year following a move from hospital people have relatively positive opinions about their circumstances, perhaps because of new physical characterisation of their environment, or because they receive a lot of attention from carers in their new placement. Following this 'honeymoon period' it could be the case that a relative degree of dissatisfaction occurs, for the next year or so, as the challenges of a new lifestyle are tackled. Finally a period of consolidation could occur about the third year post discharge onwards. Results from the present study could, in some way, go towards this explanation. However, as Beswick (1992) points out other explanations for the results found, could be an enhanced acquiescence effect, or a cognitive dissonance effect for people who had recently moved. There was a consistent difference between the two groups following the move to community settings for the subject group which was maintained up until 24 months. The fact that the control group showed an improvement in rated satisfaction at 30 months remains unclear. The instrument may be sensitive to small changes taking place in the living environment as well as other external factors.

Despite some of the difficulties encountered in the assessment of health and well-being, the present study sought to ensure a subjective evaluation of this facet of quality of life from the participants themselves (e.g. Borthwick Duffy, 1992; Felce and Perry, 1995a).

This is an area often neglected in the literature although similar attempts have been made by other investigators through the use of unstructured interviews (e.g. Ryan and Walker, 1993), structured interviews schedules involving the use of rating scales (e.g. Donnelly et al, 1994) or asking staff to rate satisfaction of service users (e.g. Stanley and Roy, 1988).

Studies report that a range of factors appear to influence user satisfaction with current placement (e.g. Hatton and Emerson, 1996). Positive factors included being independent and participating in domestic tasks (e.g. Booth et al, 1990; Holland and Meddis, 1993), privacy and pleasant surroundings (e.g. Donnelly et al, 1994; Wing, 1989) and being with friends (e.g. Donnelly et al, 1994). While not identified by the present study some negative factors relating to user satisfaction have been found such as lack of money (Donnelly et al, 1994; Flynn, 1989), being with incompatible residents (Donnelly et al, 1994), isolation and harassment by people in local communities (Booth et al, 1990; Flynn, 1989) and poor food (Wing, 1989). Despite some of these negative factors associated with living in the community people did not wish to return to the hospital setting (Donnelly et al, 1994; Flynn, 1989).

If satisfaction is a measure of comparison, one might expect that socially devalued people, whose circumstances, status and options to date may make them particularly prone to having low expectations, may be the most likely to report satisfaction under adverse life conditions. Felce and Perry (1995) point out that research on adults with moderate or mild learning disabilities living relatively independently has provided a picture consistent with this expectation. Studies have shown that people remain satisfied about the present and remarkably optimistic about the future despite the adverse conditions under which they live including: poverty, poor housing, threats to health, threats to safety, victimisation and social isolation (e.g. Close and Halpern, 1988; Edgerton, Bollinger and Kerr, 1984; Flynn, 1989).

While the present study has used the concepts of life satisfaction and morale interchangeably, George (1979) points out that such usage blurs important conceptual distinctions among these concepts. Life satisfaction has been defined as

assessment of the overall conditions of existence as derived from a comparison of one's aspirations to one's actual achievements (Campbell, Converse and Rodgers 1976). Life satisfaction is essentially a cognitive assessment of one's progress towards desired goals. Morale is defined in the dictionary as one's mental condition with respect to courage, discipline, confidence, enthusiasm and willingness to endure hardship (Webster, 1968).

The assessment of life satisfaction and morale in the general population is complex (e.g. George, 1979). The use of the terms morale and life satisfaction here are intended to refer to the person's own view of their situation. Further work is needed on these concepts and how best to address them for people with learning disabilities. However, the present study contributes to the overall picture of Health and Well-Being despite some of the methodological and conceptual problems.

Quality of Care

As predicted, people who were relocated into the community to small staffed houses moved into accommodation that was more materially 'enriched', had greater degrees of privacy and more resident focused management practices than that provided by the hospital. No attempt was made to examine any differences within the different types of community residences, mainly because the numbers in some of the settings were quite small. The vast majority of people moved to small staffed houses, while a few moved to larger residential units, Part IV accommodation for the elderly and community carer placements.

The results from the measures of living environments and lifestyles showed clear and immediate improvement for people leaving hospital to live in the community relative to those who remained. Findings from the analyses examining settings over time show some variation for people who moved into the community. While there was a significant initial improvement in their quality of environment and lifestyle on discharge which was maintained, further increases and decreases occurred at different stages of follow up.

Variations within the different community settings may have contributed to this but no firm conclusions can be drawn from these data. The issue of ceiling effects may

account for the lack of consistent continued progression over time for people living in the community. This could be considered the case for the assessment of living units where group mean scores in the community were only a few scores off the maximum obtainable.

However results from the assessment of lifestyles, while showing an immediate increase on discharge, did not reach anywhere near the maximum score possible on follow-up in the community. This begs the question as to what people should expect to achieve in these areas. Given that the scales were developed on the basis of areas considered important to people with learning disabilities and people in the wider community, the improvements demonstrated may still fall short of what people aspire to.

These measures were specifically developed for the present study (described in Chapter 5) within the context of a social validity framework and addressed the point made by Schwartz and Baer (1991) about the need to sample and gather greater breadth of consumer and community views about what is deemed important. The approach adopted here is somewhat novel in the field of learning disabilities but one that is increasingly referred to in the quest for an effective approach to quality of life assessment (e.g. Felce and Perry, 1995a).

While the measures discriminated effectively between the hospital and community settings, the weighting of items regarding their relative value was not within the scope of this study. Rather an overall picture emerged in relation to living environments and lifestyles in areas considered important by both people with learning disabilities themselves and the wider community.

While different approaches have been taken in other studies regarding the assessment of living environments and lifestyles, some comparisons with the findings from the present study can be made.

Most studies typically used rating scales such as PASS 3 (Wolfensberger and Glenn, 1975), and Environment Checklists (Knapp et al, 1992) to determine the degree of 'normalisation' of the residences (e.g. Connelly et al, 1992; Felce and Perry, 1997),

the general appearance, homeliness and cleanliness of the residences (e.g. Raynes and Sumpton 1987) and the quality of the internal environment of residences (e.g. Felce et al, 1985).

In 10 studies reviewed by Hatton and Emerson (1996), comparing service models, nine studies found that hospitals were more institutional and less attractive in appearance than hostels or group homes and had a poorer material environment for service users (e.g. Donnelly et al, 1994) with one study finding no difference in appearance between hospitals and hostels (Wing, 1989).

While few differences were apparent within hospital settings there was a wide variation in the physical environment within community settings for both hostels and group homes (e.g. Cambridge et al, 1994; Perry and Felce, 1994; Felce and Perry, 1997; Sinson, 1990).

Further differentiation was evident between types of community settings, with staffed houses, in some cases, providing the most normalised environments (e.g. Beswick, 1992; Connelly et al, 1992). There is also some evidence that more homely and less institutional environments were provided for people with greater skills and abilities (e.g. Dalgleish, 1983; Felce and Perry, 1997) with a recent study of 14 houses in Wales (Felce and Perry, 1997) indicating that smaller residences serving more able residents were associated with higher quality of service as assessed by PASS 3. Cambridge et al, (1994) found some support for the suggestion that the quality of physical environment in the community declines over time. The present investigation found no evidence of this in either hospital or community setting over the duration of the study.

The measure of personal presentation did not discriminate between people living in hospital and the community with few problems in this area being identified for either group. This is consistent with other findings (Beswick, 1992; Donnelly et al, 1994). It would seem therefore, that people living in hospital and community settings do not 'deviate' from so called normal appearance - an important issue in relation to community integration.

Overall, the findings from the present study support the evidence from other studies in that there was an immediate improvement in quality of living environments and lifestyles for people relocated to community settings. Some variation within community settings may have occurred but this was not part of the investigation.

Summary

This study examined changes in relation to quality of life for three main groups of dependent variables over a 6 year period. Individual participants joined the study at different stages, dependent on discharge arrangements and each was followed up on six separate occasions for up to 30 months. The measures used were designed to assess the multidimensional nature of quality of life for people with learning disabilities incorporating both objective and subjective methods of evaluation. Objective evaluation presented less of a challenge with this group although the subjective component was considered crucial to any meaningful evaluation of people's lives and living conditions. Some of the difficulties encountered in this area were discussed although the findings do contribute to the overall picture and underline the necessity of incorporating and developing appropriate measures such as well-being and satisfaction for this client group.

As a group subjects showed obvious improvement with respect to quality of care, partial improvement in the area of competence and personal growth and, in the main, no change on health and well-being (except on the measure of morale and life satisfaction). A deterioration was found for maladaptive behaviour. The control group showed no change in the area of competence and personal growth or quality of care. Limited changes were found for health and well-being with a significant decrease in reports of anxiety and depression. However, this may be to do with the reliability and validity of these measures with a learning disabled group rather than evidence of any change per se. These results are consistent with a number of other findings and support the view that the enriched environment of ordinary housing was insufficient on its own to increase or sustain skill development.

It would seem that measures are differentially responsive to change following relocation to the community. Some of course, may not be sensitive enough for the

small changes that may take place and, while some of the results were not statistically significant it doesn't mean that for some people a change was not clinically significant or qualitatively better. The range of abilities represented in both subject and control groups may mask particular differences between people of differing abilities. There is some evidence of a relationship between change or improvement in outcome and people's abilities and behavioural characteristics (Beswick, 1992; Landesman Dwyer, 1983; Hemming, 1986; Shal and Holmes, 1987) although this was not examined in the present study. However, as the control group were matched on a number of variables, including behavioural characteristics, this lends support to the results where significant differences between the groups were found.

Another reason for differences between the measures is one of measurement validity - does the measure actually measure what it is supposed to measure? Given that the majority of measures are both valid and reliable as they are related to aspired outcomes for community services (cf NDG 1980; O'Brien 1987; Wolfensberger 1972) and have been utilised in similar studies - it is assumed therefore that the measures, in the main, measured what they were supposed to measure. The exceptions to this are probably those measures concerned with mental health and psychological states which were found not to be very reliable or valid for this population.

Traditionally quality of life is measured by a quality of life scale study. Many measures relevant to the assessment of quality of life and separate aspects can be assessed using different measures allowing variation of the method of data collection. A key research task is now to compare different ways of measuring similar entities so that their relative properties can be established (cf Felce and Perry, 1995a).

In the same way that broad agreement on the definition of quality of life is required, it is also important to establish related measurement methodologies which can command broad support. Perry and Felce (1996) looked at the extent of agreement between different objective measures and measurement methods of quality of life such as material and social well-being or personal development to explore the

correlation in the rank order of settings which they generate. This type of research would establish the extent to which ostensibly similar measures do measure the same thing and precisely how they differ, if they do not.

The need to address the social validity of measures used to assess quality of life is important. It is of interest that the two measures employed in the present study which seemed to discriminate best between hospital and community settings were developed in the context of a social validity methodology with reference to a learning disabled population and a cross-section of the general population. We can therefore conclude, with some confidence, that relocating people from hospital to community settings does improve some aspects of their lives. The challenge is to ensure that all aspirations of service users, their families along with service providers are met.

A number of implications arise from the present study:

1. Firstly and probably the most important, is how best to gain subjective views. It is clear that people with profound learning disabilities will be unable to express their satisfaction with global quality of life concepts. Evaluation studies will require to consider how best to access subjective views and feelings of people with learning disabilities. The present study sought to gain this subjective dimension although with limited success. The collation of self-report data was aided by the structured interview format adopted for the present study. While some of the questions required a yes or no answer, efforts were made to check out that the individual understood the questions and the consequences of the answers. There is some evidence that use of a yes/no format results in a presentation order bias towards the last response choice (Sigelman et al 1993). Other imaginative ways of assessing self-report information needs to be considered in future studies.

2. A longitudinal approach to evaluation of this type is crucial. Individuals in the present study were followed for up to a 30 month period in their lives. While this represents a reasonable timescale further follow up may have revealed differential changes over time.

3. The present study did not purport to measure all aspects concerned with quality of life. Particularly important areas, such as community presence or integration, were not investigated. There is a need to examine further the behaviour and skills which will enable people with learning disabilities to meaningfully relate to their community.

4. The study design did not allow for an examination of within community settings. It is obvious that not all community settings are similar, even those based on the same model such as small staffed houses. Differential outcomes may well be associated with different management arrangements and style.

5. The identification of specific resident characteristics and how they relate to outcome seems relevant and important to include in future research.

CHAPTER 9

THE STUDY METHODOLOGY - STUDY 3

An evaluation of changes in resident engagement and patterns of staff/resident interaction brought about by the relocation of people with a learning disability from hospital to community residential establishments.

The Experimental Hypothesis and Research Design

The overall hypothesis of the study was that there would be improvements experienced in levels of appropriate engagement and in the rate and quality of interactions for people with learning disabilities who left hospital to live in the community relative to any (or no) changes experienced by people who remained in hospital.

The study was based on the research design described in Chapter 6 which allowed for the examination of the effects of relocation for a sample of people moving from hospital to live in the community and for a sample of people with similar characteristics remaining in hospital. For both groups, repeated measurement over time of the specific variables under investigation provided a longitudinal focus to the hypotheses under study utilising a repeated measures design across participants (Campbell and Stanley, 1966) and a matched control group design. Data were collected on five occasions at six monthly intervals - baseline, 6 months, 12 months, 18 months and 24 months.

A number of specific hypotheses were examined for people moving from hospital to community settings:

- there would be an increase in appropriate resident behaviour;
- there would be a decrease in neutral and inappropriate behaviour;
- there would be an increase in staff initiated interaction towards residents; and
- there would be an increase in peer interaction amongst residents.

For people remaining in hospital over the duration of the study there would be no change in the above.

The study also sought to examine:

- the relationship of staff interaction to resident behaviour;
- the relationship between resident characteristics, resident behaviour and patterns of interactions experienced;
- the relationship between staff - resident ratios and patterns of interaction experienced by residents; and
- the relationship between staff - resident ratios and resident engagement.

No specific experimental predictions were made concerning changes in the above but rather the study aimed to extend the body of research available and to draw some conclusions as to the nature of interactions taking place between care staff and residents across different residential settings.

The study was carried out in the context of the discharge arrangements detailed in study 2.

Participants

Identification of Subjects and Controls

Participants in the study were 41 people with a learning disability resident in Lynebank Hospital at the beginning of the project. These 41 people were a sub group of the 100 people described earlier and were selected so that the range of resident characteristics, detailed in Study 2, was representative. Of the 41 participants, 23 people identified for discharge from the hospital were the 'subjects' with 18 people who were not leaving hospital at the time, selected as controls. Individuals joined the study at different times dependent on discharge arrangements. It was the intention to have equal numbers in both groups but as with study 2, a number of the 'control' group were later selected for discharge, hence the slightly larger number in the subject group at the outset of the study.

Tables 59 and 60 present the characteristics of the 41 participants. Detailed information on individual participants is provided in appendices 24 and 25. There were 14 females and 9 males in the subject group and 12 female and 6 males in the control group. The age range was 22 - 70 years with a mean age of 35 years for subjects and 38.5 for controls. Information on medical diagnosis (ICD-10 WHO 1992) indicated that 65% of subjects and 72% of controls were described as moderately or severely retarded. Mean length of hospital stay for subjects was 22.6 years and 22 years for controls.

Adaptive behaviour was assessed by the Adaptive Behaviour Scale (Nihira et al, 1974) with a mean adaptive behaviour score (Part 1) for subjects of 146.6 (median 157) and for controls of 144.4 (median 146)

Table 59

Subject/Control Characteristics, Age,
Length of Hospitalisation, Level of Disability

	Subjects N = 23		Controls N = 18	
	No.	%	No.	%
Age (years)	8	35	3	17
20-30	11	48	10	56
31-40	1	4	3	17
41-50	2	9	0	
51-60	1	4	2	10
60+				
Mean and SD	35(11)		38(12)	
Median	33		33	
			0	
Years in Hospital				
		%		%
Under 5	0	0	3	17
5-10	0	0	0	0
11-15	0	0	2	10
16-20	10	43	3	17
21-25	7	30	4	22
Over 25	6	27	6	34
Mean and SD	22.6 (5.0)		38.4 (9.0)	
Median	21		21	
Diagnosis				
Borderline	0		1	
Mild	4		3	
Moderate	10		4	
Severe	6		9	
Profound	3		1	

Table 60

Subject/Control Characteristics -
Summary of Total Scores on the Adaptive Behaviour Scale (ABS) Part One

	Subjects	Controls
Range	48-220	57-237
Mean and SD	147 (57)	144 (52)
Median	157	146

As explained earlier, there was some difficulty in matching subjects and controls on all the variables. However, it was considered that both groups were reasonably similar at the outset to allow for later comparisons to be made.

The Mann Whitney U Test (Siegal, 1956) was administered to test the hypothesis that subject and control groups were drawn from the same population for the identified variables. No significant differences were found for age ($P = 0.1294$); length of hospital stay ($p = 0.7421$) and ABS (Part one) total scores ($P = 0.4150$). The hypothesis was therefore supported.

The numbers in the subject and control groups decreased at later data collection points as shown in Table 61. At the first and second data collection point (baseline and 6 months) there were 23 subjects and 18 controls. At 12 months and 18 months the subject group had dropped to 19 and 11 respectively and by 24 months there were 11 subjects and 8 controls. The higher number in the control group at 18 months came about because of delays with discharge arrangements for a number of the subjects (described in chapter 6). Data continued to be collected for the control group. Data were collected up to 42 months (for eight individuals) but the numbers were considered too small for meaningful analysis. The individual characteristics of subject and control groups at each assessment are displayed in Table 62 below.

Table 61

Number of Subjects and Controls at Each Data Point

Assessment Number	Time (in months)	Subjects	Controls
1	0 (baseline)	23	18
2	6	23	18
3	12	19	18
4	18	11	18
5	24	11	8

Table 62

Subject/Control Characteristics - Mean Scores for Age, Length of Hospitalisation, ABS (Part 1) at each assessment

	Subjects				Controls			
Assess-ment Number	Nos.	Mean Age	Mean Length of Hospital-isation	Mean ABS Total (Part 1)	Nos.	Mean Age	Mean Length of Hospital-isation	Mean ABS Total (Part 1)
1	23	35	23	147	18	38	22	144
2	23	35	23	147	18	38	22	144
3	19	36	23	150	18	38	22	144
4	19	35	22	150	18	38	22	144
5	11	35	22	150	8	37	20	120

Data are presented for each group as a whole, with the means calculated from the different number in each group at each data point.

The Friedman test was applied to test the null hypothesis that the subject group was drawn from the same population over assessment 1 to 5 (i.e. the 23 subjects at T1 were similar to the 11 at T5 on matched characteristics) and similarly calculated for the control group.

Chi squares and significant levels for variables under examination are presented in Table 63. There are no significant differences within subject and control groups on matched variables.

Table 63

Chi square and Significance Levels for Subjects and Controls for Age, Length of Hospital Stay and ABS (Part 1 Total)

	Subjects			Controls		
	Chi Square	D.F.	Significance	Chi Square	D.F.	Significance
Age	3.2000	4	0.52	1.8000	4	0.61
Length of Hospital Stay	2.3000	4	0.68	2.4000	4	0.5
ABS (Part 1 Total)	9.800	4	0.04	2.7000	4	0.44

Consent was sought from each participant and the procedure adopted is described in Study 2. One subject withdrew consent at assessment 3 (12 months) and no further data were collected.

Settings

The settings are described fully in study 2. All of the participants were residents in Lynebank Hospital at the onset of the study. The 23 subjects were discharged to six different staff group homes across Fife with between 3 and 5 residents each.

Procedure

Development of Observation Schedule

The observation schedule was developed on the premise that both resident and staff behaviours are important in the assessment of quality of life for people with learning disabilities. It has been recognised now, for some time, that direct observational measures of behaviour can make an important contribution to the evaluation of service quality (e.g. Mansell, 1985). There is evidence that the sensitivity of interview-based ratings may be inadequate to detect changes in aspects of quality of life. Also direct observation of resident behaviour has been

found to be more reliable than other methods of measuring engagement such as diaries of user activities (Joyce et al, 1989).

Direct observation has been used to evaluate large scale deinstitutionalisation programmes (e.g. Felce, Kushlick and Mansell, 1980; Landesman-Dwyer, Sackett and Kleinman, 1980; Hemming, Lavender and Pill 1981). Specifically, direct observation of the extent to which users are actually engaged or participating in everyday on-going activities has been the most frequently used measure of outcome in U.K. research over the past 16 years (e.g. Auburn and Leach, 1989; Beail, 1988; Bratt and Johnson, 1988; Emerson et al, 1992, 1993; Felce et al, 1980, 1986; Mansell and Beasley, 1990; Wood, 1989).

These observational studies have recorded the activity of service users in a number of pre-defined categories. Engagement is typically defined as either appropriate non social activity (e.g. participation in leisure activity; personal care, domestic activity) or social interaction between the user and others (e.g. Felce et al, 1986).

The use of 'engagement' as a measure of service effectiveness has been justified by a number of researchers. Whitaker (1989) argues that at a general level the personal satisfaction derived from 'adaptive engagement' with the environment leads to an automatic improvement in quality of life, while Mansell et al (1987), and Wolfensberger and Thomas (1983) suggest that there are obvious benefits for education and development if opportunities to interact with the environment are available.

The most broadly used resident behavioural categories have tended towards a definition of appropriate behaviour, inappropriate behaviour and neutral behaviour (e.g. Beswick, 1992; Cullen et al, 1983; Felce et al 1986; 1987 Felce and Repp, 1992; Mansell and Beasley, 1993) with some studies focusing on specific aspects of appropriate behaviour such as participation in domestic activity, leisure activities, day activities (e.g. Booth, Simons and Booth, 1990;

Felce and Perry, 1994; Malin 1983; Raynes and Sumpton, 1987;) and/or inappropriate behaviour such as challenging behaviour (e.g. Emerson et al, 1993; Mansell, 1994; Thomas, 1986).

Whatever specific categories of behaviour are employed it is generally assumed that the aim is to increase the amount of appropriate behaviour and to decrease the amount of neutral and/or inappropriate behaviour.

In addition to the focus on resident behaviour a number of researchers have addressed the direct observation of staff behaviour, particularly as it impacts on resident behaviour (e.g. Cullen et al, 1983; Felce et al, 1989; Wood, 1989).

A contingency analysis of behaviour suggests that the behaviour of direct care staff will have an important effect on the frequency of different categories of resident behaviour, so it becomes important to categories the reactions of staff to particular types of resident behaviour (e.g. Cullen et al, 1983). Several studies have addressed the issue of increasing specific ward staff behaviours in order to have them control certain resident behaviours (e.g. Reid and Whitman, 1983; Seys and Ducker, 1986). There is also the view that residents extend control over certain staff behaviours (Duker et al, 1989).

At a more general level it is now well recognised by the professionals that the quality of interpersonal interactions of people with learning disabilities form a fundamental feature of good quality care (Calculator 1988) and for people with learning disabilities who live in staffed situations the staff are the primary mediators of interaction.

The observation schedule developed for the present study aimed to:

- address key aspects of resident behaviour as it pertains to quality of life;
- examine staff behaviour as it relates to resident behaviour;
- provide an exhaustive description of resident behaviour;

- examine the extent of resident contact with others residents;
- allow for meaningful comparisons with other studies (the definition of engagement has been used with sufficient consistency across studies to allow for comparison of results e.g. Emerson and Hatton, 1994);
- examine the relationship between staff and resident behaviours;
- allow for a valid and reliable measure across different settings; and
- allow for ease of recording across different settings.

1) Resident Engagement

Three broad categories of resident behaviour were selected based on the work of other researchers (e.g. Beail, 1985; Beswick, 1992; Cullen et al 1983; Felce et al 1986;) - appropriate (or engaged), neutral and inappropriate behaviour. These were defined further as:

Appropriate - behaviour which is normatively valued or is likely to lead to the acquisition of normatively - valued repertoires. For example self care, social, leisure or domestic activity.

Inappropriate - this is behaviour which is normatively devalued and is seen as inappropriate for an adult living in Britain. Examples are aggressive behaviour such as physical assault, unnecessary shouting; childish behaviour which is not likely to lead to the acquisition of normatively - valued repertoires; stereotyped or self injurious behaviour; bizarre behaviour such as talking to oneself or excessive pacing; any behaviour resulting in danger to other people or destructive to the environment.

Neutral - This is behaviour which does not fit either of the above categories. A main contributor is likely to be inactivity.

There was no attempt to sub-categorise behaviour further as it was felt that the use of the 3 main categories would provide the information on client engagement required for the present study.

The use of these definitions rests on the cultural context of behaviour (e.g. Cullen et al, 1983). Behaviour can be described in relation to two broad and overlapping sets of criteria:

a) clinical educational, or the extent to which it helps the person to acquire more satisfying (from the standpoint of client and/or society) behaviours and experiences and (b) systemic, or the extent to which it helps the person to become accepted within the mainstream of society. Cullen et al(1983) point out that the systemic perspective while subsuming the clinical educational, raises the issue of the relationship between society (or the community) and the client and draws on the work of Wolfensberger (e.g. Wolfensberger 1972).

The behavioural definitions collectively provided an exhaustive set in that one resident behaviour was registered at all times. They were not, however, mutually exclusive; although in general appropriate behaviours are incompatible with inappropriate behaviour. If two behaviours occurred together, the rule adopted was to record the most salient i.e. the one which was having most effect on the environment. For example, if a resident was talking to himself in a childish way while simultaneously pouring a cup of tea, this would be recorded as appropriate.

2) Staff Behaviour

This study was concerned with the relative frequency in which care staff reacted to resident behaviour and did not examine all staff behaviour. Of particular interest was the extent to which staff reacted to residents' behaviour in ways which were positive or negative. Other studies have looked at staff behaviour in similar ways (e.g. Cullen et al, 1983) and a number of studies have employed

staff behaviour categories to record detailed interactions (e.g. Felce et al, 1986; Felce, Lowe and. Blackman, 1995; Hile and Walbran, 1991; Wood, 1989). There is either an implicit or explicit assumption that certain staff behaviours are more beneficial to residents than others and that certain interactions can lead to higher levels of resident engagement (e.g. Felce et al, 1995, Mansell, 1995).

For the purpose of the present study staff categories were kept general. However, in evaluating the qualitative component of the interaction the focus was on those staff interactions that allowed for a response from the resident and those that did not. This formulation of interaction has been developed from the mother-infant interaction studies on turn taking, (discussed in chapter 3), which have shown that types of interactions which the developmentally young experience are important to the development of communication and socialisation (e.g. Jones, 1977, 1980).

Ware(1987) extended this concept to a study of children with severe and profound learning disabilities and examined interaction with respect to those interactions that allowed for dialogue or an appropriate response and those that did not. The extent to which an environment is one which adults make initiations allowing for dialogue is an indication of its potential for promoting the intellectual and social development. In the knowledge that rates of interaction between care staff and people with learning disabilities are often low, particularly in hospital settings (e.g. Cullen, 1983; Poole et al, 1979; Wright et al, 1974) evaluating the 'quality' of these infrequent interactions was considered an important facet to the overall assessment of quality of life.

Staff behaviour was categorised in the following way:

Positive Attention - Any response or initiation to the resident which would normatively be called positive. This includes ordinary conversation, overt praise, affection and listening and was subdivided into two categories:

(i) an interaction allowing for a response e.g. open interaction

(ii) an interaction not allowing for a response e.g. closed interaction

Negative attention - Any response to the resident which would normatively be called negative. Instruction to desist, censure, contradiction are included as are physical sanctions or removal from the situation.

3) Resident Interaction

The nature of interactions between residents has received less attention in the literature. It is assumed that providing more 'normalised' services will lead to a significant improvement in the quality of experiences for people with learning disabilities. One could expect that living in small community residencies would enhance the possibilities for a person with learning disabilities to interact with others and develop a broader spectrum of interpersonal interaction and relationships.

A general approach was taken to the assessment of resident interactions to provide a 'picture' of the nature of interactions between residents in the different settings.

The reaction of other residents was recorded in a similar way as for staff.

Negative attention - e.g. physical or verbal abuse directed at resident
Positive attention - e.g. conversation, interacting in groups, doing a piece of work together.

4) Relationship of Staff Interaction to Resident Behaviour

While it was outwith the scope of the present study to apply a sophisticated sequential analysis methodology the categories of behaviour were defined in a

way to allow the relationship between staff and resident behaviours to be examined. Particular questions of interest were for example:

What categories of resident behaviour attracted staff attention?
When staff interacted with residents what category of resident behaviour followed?

Observational Procedure

Examination of the literature on observational research (e.g. Sackett, 1978) demonstrates the need to take account of a number of factors in selecting procedures, including sampling techniques, equipment and observer training.

Sampling

It is recognised that naturalistic observational strategies yield the most relevant data (Lytton 1980) and that it is necessary to sample streams of behaviour even though there are errors with the main procedures of interval and momentary time sampling (Harop and Daniels, 1986; Mansell, 1985).

The question of what sampling procedure would best address the research questions being posed had to be considered with the constraint that only one observer would be available for the majority of the time.

Resident and staff behaviour have often been sampled in two ways - duration and rate. Harrop and Daniels (1986) recommend sampling for duration to provide a more accurate estimate of absolute levels of behaviour. An investigation may only be concerned with how often certain events occur or in what order they occur and are not much concerned with how long they last. At other times, duration, the mean amount of time a particular kind of event lasts or the proportion of time devoted to a particular kind of event is very much of concern.

As a result many writers have found it convenient to distinguish between frequency behaviours on the one hand and behavioural states or duration behaviours on the other hand (Altman, 1974; Sackett, 1978).

Interval and momentary time sampling procedures have been most often employed in this type of research - however these procedures do not allow the complete sequence of interaction to be preserved. Methodological drawbacks of interval measures have been well documented (Repp et al, 1976; Sanson-Fisher, Poole and Dunn, 1980). Momentary time sampling is often the produce of choice - but can lead to over and underestimates of duration of behaviour (Mansell, 1985; Repp, Barton and Bruille, 1982).

The most appropriate technique for the present study was therefore considered to be continuous real time observation of individual residents. By using this method a more complete picture could be obtained of resident behaviour and the sequence of interactions also preserved.

Given the constraints of time and resources consideration had to be given to how long an observation should be in order to provide a representative sample of what is occurring and when the observation should take place. Little information is available concerning these actual variables (e.g. Walbran and Hile, 1988) and researchers have employed a range of methods, for example, observing residents continuously for a number of hours at a time (e.g. Felce et al, 1986) or for several shorter periods during the day (e.g. Cullen et al, 1983). Walbran and Hile (1988) found that observations of 15 minutes duration yielded the same information as observations of 30 minutes and concluded that five 15 minute week day observations of behaviour at various locations provided reliable representative information concerning resident and staff interactions.

Observational data for the present study were collected over six 15 minute sessions between 8.00 a.m. and 7.00 p.m. for each participant at each data point (T1 - T5). This yielded 90 minutes of direct observational data for each

participant at each assessment phase (baseline, 6 months, 12 months, 18 months and 24 months).

Observation sessions were chosen to be representative of the residents' day and the activities taking place.

Table 64 below shows the time (in hours) spent in direct observation of both subjects and controls over T1 - T5. A total of 262.5 hours of direct observational data were collected.

Table 64

Direct Observation Total Time (in hours) for Subjects and Controls T1 - T5

	Baseline	6 months	12 months	18 months	24 months
Subjects	34.5	34.5	28.5	28.5	16.5
Controls	27	27	27	27	12

Total for Subjects = 142.5 hours

Total for Controls = 120 hours

Walbran and Hile, (1988) identified location as a primary determinant of the nature of interactions. Prior et al, (1979) found that 'structured' situations provided more verbal interaction between staff members and residents than did 'unstructured' situations. Structured situations were defined as those requiring *purposive* activity, usually under staff supervision.

Pettipher and Mansell, (1993) found 90% of all staff contact with clients in a day centre was task related i.e. took place in a structured setting.

The present study sought to examine the rate and nature of interactions across different setting conditions as 'resident' and staff behaviour may well vary as a function of the different conditions.

The two general setting conditions of 'structured' and 'unstructured' were chosen. In addition, a third condition, mealtimes, was also included. Inclusion of mealtime observation was felt to be important as there is recognition that institutional practices have traditionally been quite dissimilar from the manner in which people have their meals in normal homes (e.g. Vanbiervtile, Sprangler and Marshall, 1981). It was therefore of interest to examine this particular situation across hospital and community settings. Of the six observational sessions for each participant, two were carried out in unstructured settings when residents were not engaged in any particular activity or task e.g. sitting in the ward or group home, spending time in own room. Two were carried out in structured settings* (a.m. and p.m.) usually the work therapy in hospital or training centre for people living in the community. The other sessions took place after breakfast and at meal times. It was felt that this provided a reasonably broad picture of a resident's day and obtained a representative view of the overall activities taking place. Individuals were not observed outwith these times or when they were engaged in any private activities such as dressing, bathing toileting etc. As a result, for a very small percentage of the time, data were not recorded (T1-T5 Subjects 3% Controls 4%). Table 65 provides details of the observational procedure.

Table 65

Observational Procedure
For T1 - T5

Location	Setting Condition	Time	Duration
Ward/Group Home	Unstructured	8.00 a.m.	15 mins
Ward/Group Home	Unstructured	a.m. (between 9 a.m. - 12 pm.)	15 mins
Work Therapy Training Centre	Structured	a.m. (between 10 a.m. - 12 p.m.)	15 mins
Work/Group Home	Mealtime	12.00 pm. - 1.00 p.m.	15 mins
Work Therapy/Training Centre	Structured	p.m. (between 2.00 p.m. - 4.00 p.m.)	15 mins
Ward/Group Home	Unstructured	p.m. (between 5.00 p.m. - 7.00 p.m.	15 mins

* A small number of the participants did not attend a structured day placement. Observation was therefore carried out in their residence and coded as unstructured

Staff : Resident Ratio

For people with learning disabilities moving from hospital to small community residences it is logical to expect that staffing levels will be higher and associated expectations are that increased staffing will lead to an increase in the number of interactions between staff and clients. Although this presumption is reasonable, it does not always hold, and several studies have shown little effect of increased staff across a wide range of settings (e.g. Barton, 1980; Dalgleish and Mathews, 1981; Repp and Tizard et al, 1972) with some showing a decrease in the number of staff initiated contacts with clients when staff numbers were increased (Mansell et al 1982). Felce et al (1991) found improvements in the level of staff interaction and client adaptive functioning when the client group decreased in size to four or under.

Staff : Resident ratio was defined as the number of residents to each member of staff within the area where the observation was taking place (e.g. ward, work therapy room, day centre room, staffed home). Each time an observation session commenced on a participant the number of staff and residents in the area was noted. The number of staff and residents in the area was noted again at the end of each 15 minute observation session. The procedure did not allow for data to be collected each time a staff member or resident moved into or left the area. If the numbers of staff and residents varied from the beginning to the end of a session an average staff : resident ratio was identified. On average the ratio of staff to residents in the hospital setting was 4 : 25 and in the community residences 2 : 4.

Apparatus

The recording of behaviour by direct observational methods has advanced with the use of data logging devices and micro-computers (e.g. Sanson - Fisher et al 1979, 1980; Repp et al, 1989). A major advantage of such devices is that data are recorded in a machine readable form from the start. Also the electronic

recording devices usually contain an internal clock which means that whenever an observer enters a code the time can be stored automatically. Observers are also free to devote their full attention to whatever or whoever is being observed - as they can learn to use the appropriate keys with little need to shift their eyes from the recording task, as they do when recording with paper and pencil.

Direct observational recording of behaviour in the area of learning disabilities has seen the use of instruments such as the MORE (e.g. Cullen et al, 1983) and the Epson Hx - 20 (e.g. Felce et al, 1986, 1987, 1991) of which the latter is a portable computer with typewriter keyboards that is specifically programmed.

More recently the 'PSION Organiser' a small hand held computer has been used (e.g. Beasley et al, 1989; Bowie and Mountain, 1993; Felce and Perry, 1995). The Psion Organiser has a number of benefits. It is small, very portable and non obtrusive. It is easily acquired from retail outlets at reasonable cost. The computer can be programmed so that different keys correspond to behaviour categories - with data being stored in real time. The data storage of the Psion was equivalent to about 10 hours of observation.

When the present study was conducted there were no commercially available programs for the Psion suitable for our observational procedure. Since then the Psion has been used more widely and appropriate software has been developed (e.g. Beasley et al, 1989).

An 'in house' programme was developed for the purpose of the present investigation.

The following information was collected at the beginning of each observational session:

- the resident observed (identification code)
- the researcher carrying out the observation

- the setting observation was taking place (e.g. hospital ward; day centre; staffed group home etc.)
- the setting condition - structured, unstructured or meal time
- the assessment number (1 = baseline, 2 = 6 months, 3 = 12 months, 4 = 18 months, 5 = 24 months)

The Psion was programmed so that three keys corresponded to the three resident behaviour categories; three keys corresponded to the three staff behaviour categories and two keys corresponded to (other) resident interaction.

Resident behaviour was an exhaustive set so at least one resident behaviour was registered at all times. Staff behaviour was recorded only when staff were interacting with the particular resident being observed. When no staff key was recorded this indicated no interaction to that resident was taking place. This was similar for 'other' resident behaviour.

A number of different programmes were written for: data collection; downloading data to the main computer; manipulating the data; analyses of sequences of behaviour and for reliability assessments.

The programme allowed the following information to be extracted:

- the category of behaviour observed;
- the length of time, in seconds that each episode of behaviour lasted;
- the total number of occurrences of each behaviour in each session and in what sequence; and
- the total length of time that each behaviour occurred within the session

The observation session began when the observer pressed the first resident behaviour key. As the Psion is programmed in real time date, session length and exact time were saved automatically. All the data were automatically stored

onto data packs which were transferred to an IBM compatible computer for analysis.

While the investigation was primarily concerned with 'duration' of the specific behaviours the 'frequency' of behaviours was also of interest. In particular the study aimed to examine the 'sequence' of certain resident and staff behaviours to identify the impact of staff behaviour on resident behaviour and vice versa.

Assessing Observer Agreement

The observers were the author and research assistants who had honours psychology degrees.

The observers were initially trained using video tapes of residents in the hospital settings. This allowed the observer to become fluent in the use of the PSION and to reach agreement about the category definitions. Prior to any formal data collection, observers collected data *'in vivo'* to become familiar with any contextual cues which might not be apparent using video recordings.

For training purposes observer reliability was assessed i.e. assessing how accurate a measure is against a standard protocol (e.g. Johnston and Bolstad, 1973). Observers rated clips of video tape and their scoring was compared to a predetermined record of behaviour as assessed by the author and a member of the psychology department with the aim of reaching at least 80% percentage agreement on categories of behaviour.

Observer agreement, however, was applied for the "*in vivio*" observations and reliability assessments were conducted by two observers who simultaneously but independently recorded the behaviour of residents and staff.

The two most popular measures of inter observer reliability in observational research are percentage agreement and Cohen's Kappa (Cohen, 1960). Kappa

has the advantage that it takes account of chance agreements, and some authors (e.g. Hartmann, 1977) argue that it should always be used in preference to percentage agreement. However, Baer, (1977) contends that percentage agreements between observers represent a useful answer to the crucial question in observational research - that is the extent to which two observers watching the same subject, see the same behaviours occurring during the same time period.

For the purpose of the present study the simpler statistic of calculating percentage agreements was employed and calculated for each code by dividing the lesser duration observed by the greater and x 100.

A number of issues in applying observer agreements in observational research were considered as outlined by Bakeman and Gottman (1986).

Accuracy versus Agreement - as discussed above accuracy was assessed at the outset for training purposes by comparing ratings against a standard protocol. However, given the nature of the study, this was not practical on an on-going basis. Agreement between two independent observers was considered satisfactory.

As the study involved a number of different observers over several years there was a need to ensure that the data collected did not vary as a function of the observer. Observer reliability was therefore calculated for each 'new' observer.

Not only do we need to ensure that different observers are coding similar events in similar ways, we also needed to be sure that an individual observer's coding is consistent over time. Some studies have found a gradual decay in reliability from the training level (e.g. Taplin and Reid, 1973). This potential problem was addressed by taking samples of 'observer reliability' throughout the duration of the study and using a 'checker' (the author) who was not involved in the majority of the observation as the second observer for the reliability assessments.

Reliability assessments were carried out on 15% of all observational sessions across the range of settings over the course of the study. Inter-observer agreement ratings were therefore available for 39 hours of direct observational data. The percentage agreements for each behavioural category are shown in Table 66.

Table 66

Direct Observations - Percentage Agreement

Behaviour Category	%
Appropriate resident behaviour	98.5
Inappropriate resident behaviour	99.0
Neutral behaviour	85.0
Positive staff attention (open)	61.0
Positive staff attention (closed)	92.0
Negative staff attention	-
Positive resident and interaction	-
Negative resident interaction	-

Other than positive staff attention (open) all behavioural categories reached an acceptable level of agreement (e.g. Kazdin, 1977).

The lower percentage agreement for positive staff attention (open) reflected the fact that staff rarely were rated on this category. No percentage agreements were calculated for negative staff attention or positive and negative resident interaction because of insufficient data being recorded.

Observer Reactivity

It is recognised that the collection of observational data could be distorted due to observer reactivity or bias (Milne and Hodd, 1983). Reactivity refers to the influence of the observation procedure on the behaviour of the subjects, and bias refers to the expectancies of the researcher to record certain patterns of behaviour. The fact that the behaviour observed may be altered by the measurement process restricts generalisability to other settings, subjects and to unobserved periods within the same setting. Dubey et al (1977) warn against

the implicit assumption that observation does not affect the behaviour of subjects.

Walbran and Hile, (1988) found no support for the hypothesis that activities of direct care staff members may change as a factor of being observed in a large institution setting for people with learning disabilities.

Various suggestions have been made to minimise reactivity. The range of options is more limited for observers in naturalistic research settings. It has been suggested that the observer be as unobtrusive as possible (e.g. Haynes and Horn, 1982; Kirmeyer, 1985) which means not interacting with the subjects of observation and indeed others in the research setting which in turn is made easier by avoiding eye contact (e.g. Beasley and Mansell, 1987). Such instructions to observers are explicit in most of the observational literature on staff and residents in residential settings for people with learning disabilities where the observer attempts to interact with the environment as little as possible. However, there is little mention of the effects of observer reactivity in small community settings. Orlowska (1990) examined the effects of the presence of an observer on staff in two small group homes for people with learning disabilities. Comments received from staff indicated that in the home for more severely disabled residents the effect of being observed was less apparent. While some staff did report changing their behaviour in the presence of an observer, more staff members felt that their behaviour was unaffected by the observer. Mansell (1995) recorded negligible levels of social contact from participants to observers in hospital and small residential units in the community.

For the purpose of the present study observers were instructed to avoid interaction with both residents and staff during observation sessions. Observers familiarised themselves with the settings and often had a number of previous visits to the ward, staffed house etc. Staff in both hospital and community settings were familiar with the on-going research project and only on occasion asked what behaviours were being observed. The observer always introduced

themselves to the staff on duty and provided a brief explanation as to the purpose of the session. Staff were asked to try and ignore the observer as much as possible and carry on as normal. In an attempt to minimise reactivity, the first few minutes of an observation session was used as a "warm up" where data was not collected but observers took up position and appeared to be involved in data collection. After some brief initial interest from residents and staff, generally subjects showed no interest in the observers. It was felt that these measures minimised the effects of observer reactivity.

Other Measures

As the participants in the present study were a sub group of the participants described in Study 2 data from the range of measures employed were available. In particular information from the Adaptive Behaviour Scale (Nihira et al, 1974) was considered useful to the analysis of interactions.

CHAPTER 10

RESULTS STUDY 3

DATA ANALYSIS AND PRESENTATION

Statistical Analysis

Data Generated

The observational data collected on resident and staff behaviours were analysed in three ways.

1. In terms of the percentage of total time each resident and staff category occupied for each setting condition (i.e. structured, unstructured and neutral) and for each assessment (T1 - T5), a percentage was calculated for each participant and these data were used for the statistical analysis (described below).

   For ease of comparison with other similar studies and for illustrative purposes the percentage calculated for each participant was then averaged across all individuals for each of the subject and control groups.

2. A sequential analysis was conducted on the relationship between certain staff and resident behaviours for 18 subjects and 18 controls. Data were generated for this analysis by identifying the frequency of a particular sequence of staff : resident behaviours occurring within a given observation session.

3. Additional data on staff : resident ratios and participant characteristics were also included and analysed in relation to resident and staff behaviour.

Design and Rationale

As with Study 2, the research was organised to allow hypotheses to be tested using two main experimental designs - a longitudinal repeated measures design using participants as their own controls and a comparative matched subjects design.

The results are reported in the following way:

- Within group analysis for subjects - longitudinal repeated measures design examining the effects of relocation.
- Within group analysis for controls - longitudinal repeated measures design examining the effects of remaining in hospital.
- Comparative matched subjects design examining any differences between the groups.

Independent / Dependent Variables

The main independent variables under investigation were the 'in hospital' and 'in community' conditions. However the examination of resident engagement and the nature of resident : staff interactions led to the inclusion of a number of additional independent variables/categories to analyse this complex area.

These were:

- setting conditions - structured, unstructured and mealtime
- staff : resident ratios
- resident adaptive and maladaptive behaviour (ABS)

The dependent variables were resident and staff behaviour as described in Chapter 9.

Analysis

As the data generated from the direct observation of resident and staff behaviours were not normally distributed - non-parametric statistical tests were selected with SPSS being the package of choice.

Within Groups

The *Friedman Two Way ANOVA by Ranks (Siegal, 1956) was employed for the within group analysis for subjects and controls. Given the differing number of subjects and controls over T1 - T5 (see Table 48) it was elected to exclude cases with missing values and to use as much of the data as possible. This was considered preferable to inserting median values for missing cases.

Follow-up to a significant Friedman was by Post Hoc Analysis (or multiple comparisons) (cf Siegal 1956). This was selected as the investigation sought to make no assumptions regarding the comparisons. Post Hoc analysis also provides a more stringent acceptance of significance reducing the likelihood of Type 1 error.

Between Group

The Mann-Whitney U test (Siegal, 1956) was chosen to examine any differences between subjects and controls and in this conttext the groups were treated as independent samples. The analysis was carried out for each assessment phase over T1 - T5.

Spearman Rank Order Correlation Coefficiants (Siegal, 1956) were calculated between:

- resident and staff behaviours;
- staff : resident ratios and 1) residents characteristics
  2) staff contact with residents
  3) resident behaviour
- resident and staff behaviours and resident characteristics

* This is referred to as the Friedman in the text.

Significance Levels

When a large number of analyses are carried out on a data set there is a danger that a number of spurious 'significant' relationships will be recorded i.e. that a number of false positions will be obtained by chance as discussed for Study 2. A significance level of 0.01 was deemed necessary for the classification of a result as significant to reduce the likelihood of Type I errors.

Data Presentation

As noted earlier the study involved 262 hours of direct observation so a considerable amount of data were gathered.

For ease of presentation data is presented in summary form with mean and median scores for both subjects and controls and is graphically represented where appropriate.

As the analysis is non parametric the use of means and standard deviations is illustrative and assists in comparison with other studies which have used these data. Friedman values are presented for each measure by chi-square, degrees of freedom and significance levels. Post Hoc analyses are presented as significance levels.

Mann-Whitney Z values and probability values (2 tailed) are presented for each measure at each assessment.

Significance levels (P) are presented as exact (to two decimal points) when greater than .05. Otherwise levels are presented as : <.05; <.01; <001 as appropriate.

The results are presented in four parts in relation to resident behaviour, staff contact and resident : resident interaction for:

I Effects of relocation

II Effects of remaining in hospital

III Comparison between movers (subjects) and stayers (controls)

IV The relationship of staff behaviour to resident behaviour.

The presentation and analysis of the data is followed by a discussion of the implications and findings.

CHAPTER 11

STUDY 3

RESIDENT ENGAGEMENT AND PATTERNS OF STAFF-RESIDENT INTERACTION

An evaluation of the effects on resident engagement and patterns of staff - resident interaction brought about by the relocation of people with a learning disability from hospital to community residential establishments.

I. The Effects of Relocation

II. Effects of Remaining in Hospital

III. Comparisons Between Movers (Subjects) and Stayers (Control)

IV. Relationship of Staff Behaviour and Resident Behaviour

1 THE EFFECTS OF RELOCATION

Resident Behaviour

The experimental hypothesis was that residents would show higher levels of engaged behaviour and lower levels of inappropriate and neutral behaviour as a result of moving from hospital to the community.

1) Appropriate/Engaged Behaviour

Comparison of total mean and median scores for engaged behaviour as displayed in Table 67 show some small group changes across T1 - T5. Engagement in appropriate behaviour increased from a mean of 35.3% (median 32) at baseline to a mean of 57% (median 54) at 18 months with a decrease to 46% (median 38) at 24 months. There was considerable individual variation between people ranging from between 2% and 66% when living in hospital to between 6% and 90% when living in the community. While the Friedman test did not reveal significance (chi-square 9.2182, D.F. 4, P = .06) there was a strong trend towards significance.

Setting Conditions

An examination of average levels of engaged behaviour across different setting conditions revealed some group changes. In structured settings there were small variations in resident engaged behaviour over T1 - T5. The Friedman reveals no significance (chi-square 3.0820, D.F.4, P =.55). Levels of engaged behaviour ranged from 0 - 100% across individuals.

Table 67

Appropriate Behaviour - Percentage Time
Medians, Means and Standard Deviations (in parenthesis)
Subjects T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	58.0 (29.0)	50.2 (29.4)	50.8 (38.6)	63.1 (21.2)	62.3 (33.0)
Median	62.5	51.5	72	55	76
Range	0-100	0-100	0-100	36-100	13-100
Unstructured					
Mean	16.3 (17.7)	37.3 (24.1)	40.0 (21.6)	45.5 (34.4)	36.5 (22.1)
Median	11	34	41	36	33
Range	0-52	0-98	1-76	2-96	4-73
Mealtimes					
Mean	62.6 (26.0)	76.2 (24.1)	82.0 (18.5)	86.0 (20.3)	76.3 (29.7)
Median	68.5	87	84	96	88
Range	7-100	42-100	35-100	47-100	16-100
TOTAL					
Mean	35.3 (19.5)	48.6 (21.0)	50.3 (22.2)	57.0 (25.4)	46.1 (20.9)
Median	32	53	59	54	38
Range	2-66	13-89	9-84	18-90	6-80

In unstructured settings group data point to an increase in the level of appropriate engagement between baseline (mean 16.3%, median 11%) and 6 months (mean 37% median 34%) with a levelling out thereafter.

Although the analysis of individual data as examined by the Friedman did not reveal significance (chi square 7.9455, D.F. 4, P = .09) there was evidence of a trend towards significance.

The levels of engagement in appropriate behaviour at meal times showed a similar pattern with residents, as a group, showing higher levels of appropriate engagement following discharge to the community - with a mean at baseline of 62.2% (median 68.5%) and at 6 months of 76.2% (median 87%) remaining

relatively stable up to 24 months. No significance was revealed by the Friedman (chi-square 6.5111, D.F. 4, P = .16).

2. *Neutral Behaviour*

Comparison of mean and median scores for neutral behaviour, as displayed in Table 68, shows some variation across setting conditions and over time.

Overall for subjects the average percentage time spent in neutral behaviour decreased from baseline (mean 45.1%, median 45%) to its lowest level at 12 months (mean 29.1%, median 26%).

Friedman shows significance (chi square 15.6727, D.F. 4, P <.01). Post Hoc testing (see Table 69) reveals that the scores at baseline and at 6 months are significantly higher than at 12 months and 18 months (P <.05) and that the score at 12 months is significantly lower than the score at 24 months (P <.05). No significance is revealed between baseline and 6 months, baseline and 24 months and 6 months and 24 months.

Table 68

Neutral Behaviour - Percentage Time
Medians, Means and Standard Deviations (in parenthesis)
Subjects T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	38.1 (28.1)	36.6 (34.0)	28.3 (27.0)	31.2 (20.5)	36.9 (32.4)
Median	33	40	16.5	32	23.5
Range	0-100	0-91	0-82	0-60	0-87
Unstructured					
Mean	60.2 (27.7)	43.5 (23.8)	37.3 (19.1)	38.8 (30.5)	44.1 (20.1)
Median	58	48	38	34	43
Range	11-99	0-90	4-62	0-90	11-80
Mealtimes					
Mean	27.3 (23.1)	18.4 (23.6)	9.2 (10.2)	9.9 (15.4)	10.9 (23.6)
Median	18	8	5.5	0	3
Range	0-93	0-70	0-32	0-47	0-75
TOTAL					
Mean	45.1 (18.3)	37.3 (18.9)	29.1 (12.7)	30.9 (21.1)	38.1(19.3)
Median	45	36	26	28	34
Range	10-80	9-75	7-58	8-56	11-69

Table 69

Post Hoc Significance Over T1 - T5 for
Neutral Behaviour (all conditions)
Subjects

	T2	T3	T4	T5
T1	NS	<.05	<.05	NS
T2		<05	<05	NS
T3			NS	<.05
T4				NS

Setting Conditions

An examination of group percentage occurrence of neutral behaviour across setting conditions points to some changes.

The average percentage time residents displayed neutral behaviour in structured settings remained quite stable over the period of the study for the group as a whole with a mean at baseline of 38.1% (median 33%) and of 36.9% (median 23%) at 24 months The Friedman reveals no significance (chi-square 3.7600, D.F. 4, P = .44).

More variation is apparent in unstructured settings. Residents as a group were observed as displaying neutral behaviour for 60.2% (median 58%) of the time at baseline with an immediate decrease apparent at 6 months to 43.5% (median 48%) and a further decrease at 12 months (mean 37%; median 38%). The Friedman reveals significance (chi-square 11.2909, D.F. 4 , P <.05) although not at the more stringent .01 significance level. Post Hoc testing shows that the percentage time residents engaged in neutral behaviour at baseline was significantly higher than at all subsequent assessments (i.e. at 6,12,18 and 24 months) (P <.05).

Levels of neutral behaviour were low during mealtimes. While there was a decrease between the group average at baseline (mean 23.7%; median 18%) and subsequent assessments with only 10.9% (median 3%) of time being spent in

neutral behaviour at 24 months, the Friedman does not show significance (chi square 7.000, D.F. 4, P = .14).

3. *Inappropriate Behaviour*

Comparison of group average time across all settings indicates that levels of inappropriate behaviour were low and changed little from baseline to follow up in the community (see Table 70). Residents engaged in inappropriate behaviour for 15.4% (median 5%) of the time at baseline dropping to 10.1% (median 4%) at 6 months but increasing to 16.9% (median 7%) at 12 months showing another decrease to 11.5% (median 3%) at 18 months. Variation between people overall ranged between 0 - 82% in hospital and from 0 - 73% in the community.

Analysis of individual data as examined by the Friedman test does not show significance (chi-square 2.1455, D.F. 4, P = .71).

Table 70

Inappropriate Behaviour - Percentage Time
Medians, Means and Standard Deviations (in parenthesis)
Subjects T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	3.0 (6.2)	8.1(17.5)	19.6 (28.6)	7.3 (31.2)	0.83 (31.4)
Median	0	0.5	4.5	4	2
Range	0-24	0-72	0-90	0-22	0-4
Unstructured					
Mean	18.3 (26.3)	14.8 (24.8)	19.5 (27.2)	13.3 (25.2)	16.3 (25.0)
Median	5	6	4	2	2
Range	0-89	0-78	0-86	0-64	0-77
Mealtimes					
Mean	14.3 (23.7)	5.3 (8.3)	8.7 (18.0)	3.7 (8.4)	9.0 (14.4)
Median	1	3	1	0	0
Range	0-80	0-37	0-63	0-24	0-39
TOTAL					
Mean	15.4	10.1	16.9	11.5	14.4
Median	5	4	7	3	1
Range	0-82	0-66	0-73	0-51	0-91

Setting Conditions

While there are group variations across setting conditions the Friedman does not reveal significance for structured (chi-square 1.8800, D.F. 4, P = .76), unstructured (chi-square 4.3091, D.F. 4, P = .37) or mealtime (chi-square 4.778, D.F. 4, P = .31).

Some of the mean increases and decreases seem relatively large between participants but less variation is apparent when median scores are compared.

Summary of Results

The results from the three measures of resident behaviour show that while the changes are generally in the predicted direction for appropriate and inappropriate behaviour they do not reach statistical significance. There is a trend towards significance for appropriate behaviour in unstructured settings only.

The percentage of time spent in appropriate behaviour increased from baseline with residents spending more of their time engaged in appropriate behaviour in community settings as opposed to the hospital setting. The most noticeable increase was found for unstructured settings which could indicate that community settings are more conducive to 'spontaneous' engagement in appropriate behaviour than the hospital or that residents are given more to do. The percentage time spent in appropriate behaviour for structured settings shows little change with higher levels of appropriate engagement found than in unstructured settings for both hospital and community settings. This is not surprising given that 'structured' settings were those which had activities and programmes for the residents. The highest level of appropriate behaviour was found during mealtimes and there was a trend for this to increase a little following the move to the community.

Levels of inappropriate behaviour overall were low and showed little change over time. Considerable individual variation accounts for some of group

increases and decreases from one assessment to the next. Neutral behaviour decreased significantly for subjects in the community but only in unstructured settings.

For neutral behaviour the experimental hypothesis was therefore supported but rejected for appropriate and inappropriate behaviour. It is apparent from the data that while the changes for appropriate and inappropriate behaviour were generally in the predicted direction there were both increases and decreases from one assessment to the next.

Staff Attention

The experimental hypothesis was that residents would receive higher levels of interaction from staff as a result of moving from hospital to the community.

No specific hypotheses were made regarding the types of interaction residents would receive from staff. There were almost no recordings made of staff negative attention so this category was excluded from the final analysis.

Staff Positive Attention

Comparison of staff total mean and median scores as displayed in Table 71 shows an immediate increase between baseline and 6 months . Staff interacted with residents in hospital for, on average, 2.7% (median 2%) of the time. This increased to 9.2% (median 6%) at 6 months and was maintained with some further increases up to 24 months. Staff interaction varied between individuals from 0% - 13% in hospital and from 0 - 33% in the community.

The Friedman test reveals significance (chi square 24.8909, D.F. 4, P <.001).

Post Hoc testing shows the percentage of time staff spent interacting with residents at baseline was significantly lower than at all subsequent assessments (i.e. 6,12,18 and 24 months, $P < .05$). Score at 6 months was also significantly lower than at 12 months and 24 months ($P < .05$). Table 72 displays significance levels for T1 - T5.

Table 71

Staff Behaviour - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Subjects T1 - T5

Staff Behaviour	Baseline	6 months	12 months	18 months	24 months
Staff Positive (Open)					
Mean	0.87 (1.2)	6.3 (7.6)	4.2 (3.6)	4.5 (2.8)	5.3 (3.9)
Median	0	3	3	4	5
Range	0-4	0-12	0-15	1-9	1-10
Staff Positive (Closed)					
Mean	1.8 (2.3)	3.0 (2.7)	7.3 (4.7)	5.6 (5.7)	6.3 (7.3)
Median	1	2	8	4	3
Range	0-5	0-12	0-15	0-17	0-24
Staff Total					
Mean	2.7 (2.9)	9.2 (8.7)	11.5 (6.4)	10.2 (5.7)	11.5 (7.9)
Median	2	6	12	11	9
Range	0-13	1-33	0-25	2-18	1-26

Table 72

Post Hoc Significance Over T1 - T5 for
Staff Interaction (Total) Subjects

	T2	T3	T4	T5
T1	<.05	<.05	<.05	<.05
T2		<.05	NS	<.05
T3			NS	NS
T4				NS

Open and Closed Staff Interaction

The percentage of time staff engaged in open and closed interactions increased in similar ways between baseline and all other assessments.

Staff interacted with residents in hospital in an open manner (i.e. allowing for dialogue) on average, for less than 1% of the time which increased initially to 6.3% (median 3%) of the time following the move to the community and was maintained near that level up to 24 months.

The Friedman test shows significance (chi-square 17.8909, D.F. 4, P <.001).

Post Hoc testing shows the percentage of time staff spent interacting in an open way with residents at baseline was significantly lower than all subsequent assessments (i.e. 6,12,18 and 24 months) (P <.05)

For closed interaction the percentage of time also increased significantly between baseline and other assessments (chi-square 18.6909, D.F. 4, P <.001) with Post Hoc testing showing the percentage of time staff engaged in closed interaction with residents at baseline significantly lower than for all subsequent assessments (P <.05). Percentage of closed staff interaction was also significantly higher at 12 months than at 6 months and 18 months (P <.05). Table 73 displays significance levels, T1 - T5, for closed interaction.

Table 73

Post Hoc Significance Over T1 - T5
Staff Interaction (closed) All Conditions
Subjects

	T2	T3	T4	T5
T1	<.05	<.05	<.05	<.05
T2		<.05	NS	NS
T3			<.05	NS
T4				NS

Setting Conditions

An examination of the different setting conditions showed some increases in average percentage of time staff interacted with residents across the different settings. Table 74 shows mean and median percentage time and standard deviations for the different conditions. The Friedman test reveals significance for unstructured condition only (chi- square 19.7818, D.F. 4, P <.001). There is a trend towards significance for mealtimes (chi-square 9.4000, D.F. 4, p =.052). No significance is found for structured settings (chi-square 6.000, D.F. 4, p =.20)

Table 74

Staff Behaviour: Structured, Unstructured, Mealtime - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Subjects T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Staff Positive (open)					
Mean	2.3 (3.7)	5.9 (8.5)	3.0 (5.1)	4.8 (3.7)	5.8 (7.4)
Median	0	3	1	4	4.5
Range	0-12	0-31	0-16	0-11	0-19
Staff Positive (Closed)					
Mean	3.8 (6.4)	3.5 (3.5)	6.6 (3.5)	5.5 (10.0)	6.0 (8.3)
Median	1	2.5	3.5	1	3.5
Range	0-25	0-13	0-32	0-30	0-22
Staff Total					
Mean	5.8 (7.5)	9.3 (7.5)	9.6 (6.7	10.3 (11.8)	11.8 (11.4)
Median	3	7.5	6.7	8	9
Range	0-26	0-34	0-47	0-39	0-30
Unstructured					
Staff Positive (Open)					
Mean	0.65 (1.1)	6.8 (10.0)	5.6 (5.6)	5.2 (4.8)	4.7 (4.5)
Median	0	2	3	4	4
Range	0-4	0-33	0-23	0-14	0-12
Staff Positive (Closed)					
Mean	0.71 (0.92)	2.3 (2.2)	6.2 (3.9)	5.4 (5.1)	4.6 (5.7)
Median	1	2	6	3	1
Range	0-4	0-6	0-15	0-15	0-17
Staff Total					
Mean	1.3 (1.6)	9.0 (0.6)	11.8 (6.9)	10.5 (7.7)	9.4 (8.6)
Median	1	5	11	6	10
Range	0-6	0-37	0-27	2-28	0-29
Mealtimes					
Staff Positive (Open)					
Mean	0.70 (1.1)	4.6 (7.6)	3.6 (8.0)	2.4 (2.8)	3.1 (4.8)
Median	0	0.5	1	2	0
Range	0-3	0-26	0-35	0-8	0-14
Staff Positive (Closed)					
Mean	1.9 (3.7)	3.7 (8.0)	9.6 (9.6)	5.4 (11.0)	13.0 (28.8)
Median	1	0	7	1	2
Range	0-17	0-30	0-57	0-37	0-93
Staff Total					
Mean	2.5 (4.1)	8.3 (12.0	13.2 (17.0)	7.7 (3.0)	16.1 (28.1)
Median	1.5	1	8.5	3.0	10.0
Range	0-18	0-45	0-57	0-39	0-93

Post Hoc testing shows the percentage of time staff spent interacting with residents at baseline was significantly lower than all subsequent assessments (i.e. 6,12,18 and 24 months) ($P < .05$) with 6 months also significantly lower than 12 months ($P < .05$). Table 75 displays significance levels over T1 - T5 for unstructured settings.

Staff open interaction and closed interaction increased at similar levels from baseline to 24 months. Friedman shows significance for staff open interaction (chi-square 17.5455, D.F. 4, P <.001) and staff closed interaction (chi-square 17.7636, D.F. 4, P <.001). Post Hoc testing showing percentage of staff open and closed interaction at baseline being significantly lower than all subsequent assessments (P <.05).

Table 75

Post Hoc Significance - Staff Interaction: Unstructured Subjects T1 - T5

	T2	T3	T4	T5
T1	<.05	<.05	<.05	<.05
T2		<.05	NS	<.05
T3			NS	NS
T4				NS

Summary of Results

The results from the analysis of staff behaviour support the experimental hypothesis that residents received higher levels of interaction from staff as a result of moving from hospital to the community.

The data from observations of staff behaviour demonstrates a very low level of reaction by staff to a resident's behaviour in hospital, typically this occurs around 3% of the time (a range of 0 - 13%). The percentage of time increases to around 10% for residents moving to community settings (range 1 - 33%).

Corresponding increases were found for both open and closed interactions between the hospital and community settings. While the percentage of time staff spent interacting with residents increased for all three setting conditions in the community, the significant increase was found for unstructured settings only.

Resident : Resident Interaction

The experimental hypothesis of the study was that there would be an increase in resident - resident interaction for people moving from hospital to the community. Very few data were generated for this measure of behaviour so resident behaviour is looked as a total rather than positive and negative interaction.

The average percentage of time residents spent interacting with each other as shown in Table 76 was very low throughout the duration of the study. At baseline residents spent 1.3% (median 0%) of the time interacting with each other showing little change following discharge with a very small increase to 2.2% (median 0%) of the time at 24 months. Over 60% of residents received no contact from other residents.

Table 76

Resident : Resident Interaction - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Subjects T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	1.1 (2.7)	1.0 (3.0)	1.2 (2.8)	0.8 (2.0)	0.26 (0.41)
Median	0	0	0	0	0
Range	0-11	0-13	0-11	0-6	0-1
Unstructured					
Mean	1.1 (2.2)	1.2 (2.8)	1.7 (3.0)	3.5 (9.5)	4.5 (11.6)
Median	0	0	0	1	0
Range	0-9	0-13	0-10	0-32	0-39
Mealtimes					
Mean	3.0 (7.8)	2.8 (7.9)	2.8 (4.9)	0.54 (1.2)	2.5 (5.1)
Median	0	0	0	0	0
Range	0-32	0-36	0-17	0-4	0-14
TOTAL					
Mean	1.3 (2.4)	1.3 (2.7)	2.1 (3.0)	0.90 (1.3)	2.2 (4.2)
Median	0	0	1	0	0
Range	0-8	0-6	0-9	0-4	0-14

The Friedman test reveals no significance over all conditions (chi-square 5.7455, D.F. 4, P = .22). No significance is found for structured (chi-square 4.3200, D.F. 4, P

=.36); unstructured (chi-square 2.4545, D.F. 4, P =.65) or for mealtime (chi-square 5.6889, D.F. 4, P =.22)

Summary of Results

The results from the analysis of resident-resident interaction do not support the experimental hypothesis that there would be an increase in the percentage of time residents interacted with each other for people moving from hospital to the community.

The very low rates of interaction make it difficult to draw any conclusion from the data. However it would appear that when residents did interact with each other a slightly higher percentage of time was observed during mealtimes.

11 THE EFFECTS OF REMAINING IN HOSPITAL.

Resident Behaviour

The experimental hypothesis of the study was that there would be no change in levels of appropriate, inappropriate and neutral behaviour for people remaining in hospital.

1) Appropriate/Engaged Behaviour

The total mean percentage time residents as a group displayed engaged behaviour changed little over assessments (T1 - T5) (See Table 77). At baseline residents spent 36% (median 38%) of their time engaged in appropriate behaviour and this only changed marginally at 24 months with a mean of 37.8% (median 34%). The highest level was found at 18 months with residents spending 49.1% (median 60%) of their time engaged in appropriate behaviour. Individual variations between people ranged from 0% - 96%.

The Friedman test does not reveal significance (chi-square 2.4889, D.F. 4, P = .65).

Setting Conditions

In structured settings residents spent 76.3% (median 75%) of the time at baseline and 68.0% (median 76%) at 24 months engaged in appropriate behaviour. An increase was observed in unstructured settings with residents spending 13.5% (median 10%) at baseline and 21.8% (median 11%) at 24 months of their time engaged in appropriate behaviour.

At mealtimes the mean was 54.5% (median 59%) at baseline changing very little over subsequent assessments.

The Friedman test did not reveal significance for unstructured (chi-square 8.8750, D.F. 4, P = .06); structured (chi-square 5.3500, D.F. 4, P = .25) or for mealtimes (chi-square 1.0800, D.F. 4, P = .90).

Table 77

Appropriate Behaviour - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Controls (T1 - T5)

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	76.3 (28.3)	76.8 (22.3)	64.3 (29.4)	66.0 (33.5)	68.0 (29.7)
Median	75	84.5	70	78.5	76
Range	2-100	39-100	6-98	2-96	24-99
Unstructured					
Mean	13.5 (17.2)	16.6 (17.8)	22.3 (22.5)	30.9 (25.9)	21.8 (24.8)
Median	10	17.5	16..5	31.5	11
Range	0-57	0-63	0-42	0-83	0-63
Mealtimes					
Mean	54.5 (23.2	52.9 (26.1)	55.0 (30.2)	73.9 (24.8)	60.0 (24.8)
Median	59	56	50	77.5	61
Range	23-81	3-99	2-100	23-100	22-100
TOTAL					
Mean	36.0 (24.6)	36.2 (19.5)	38.4 (23.8)	49.1 (26.7)	37.8 (20.7)
Median	38	38	40	60	34
Range	0-82	1-65	3-84	8-96	10-62

2) Neutral Behaviour

Comparison of total average percentage time spent in neutral behaviour, as displayed in Table 78 shows a tendency for a slight decrease over T1 - T5. The mean percentage time at baseline was 41.1% (median 37.5%) and at 24 months 27.6% (median 32%). Variations between individuals ranged from 10% - 80% The Friedman does not show significance (chi-square 4.000, D.F. 4, P = .41).

Setting Conditions

The highest level of neutral behaviour was apparent in unstructured settings with a mean percentage time at baseline of 59.8% (median 62%) with a tendency to decrease over subsequent assessments to 38.2% at 24 months (median 36%). Neutral behaviour remained relatively low for structured settings with a mean percentage time at baseline of 21.6% (median 14%) and 16.0% (median 8%) at 24 months. A tendency towards a decrease over T1 - T5 was also evident for mealtime with a mean percentage time of 32.9% (median 32%) at baseline reducing to 20.4% (median 16%) at 24 months . The Friedman test does not show significance for structured (chi-square 4.8500, D.F. 4, P = .30); unstructured (chi-square 1.7230, D.F. 4, P =.79); mealtime (chi-square 2.200, D.F. 4, P =.70).

Table 78

Neutral Behaviour - Percentage Time
Means, Medians and Standard Deviations (in parentheses)
Controls T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	21.6 (28.0)	18.8 (21.0)	22.7 (26.3)	24.3 (22.4)	16.0 (21.3)
Median	14	10	16	29	8.5
Range	0-98	0-59	0-94	0-63	0-56
Unstructured					
Mean	59.8 (31.4)	53.2 (25.1)	48.1 (21.5)	44.3 (26.4)	38.2 (28.2)
Median	62	53.5	49.5	48.5	36
Range	10-100	14-99	14-86	1-92	3-84
Mealtimes					
Mean	32.9 (20.1)	24.0 (22.6)	25.8 (21.5)	18.1 (20.6)	20.4 (21.8)
Median	32	16	20	9	16
Range	0-75	0-66	0-75	0-61	0-69
TOTAL					
Mean	41.1 (22.6)	39.6 (17.5)	36.7 (16.8)	32.7 (17.9)	27.6 (17.9)
Median	37.5	34.5	32.5	29.5	32.0
Range	10-80	11-70	13-96	4-69	3-61

3. *Inappropriate Behaviour*

The average percentage time residents, as a group, engaged in inappropriate behaviour is low and changes little between T1 - T5 (see Table 79), with a mean score of 21.1% (median 3.5%) at baseline and a mean score of 29.1% (median 5%) at 24 months. Considerable variation between people was apparent ranging from 0% - 87%. The Friedman test does not show significance (chi square 3.2667, D.F. 4, P =.51). As with the subjects, comparison of median scores rather than mean scores points to low rates of inappropriate behaviour.

Setting Conditions

The lowest level of inappropriate behaviour is evident in structured settings (median 0 - 4%) with unstructured settings showing slightly higher levels (median 3 - 19%). Little inappropriate behaviour was observed during mealtimes (median 0% - 2%).

The Friedman test does not reveal significance for structured (chi-square 4.6500, D.F. 4, P =.33) and unstructured (chi-square 2.9750, D.F. 4, P =.56). There is a trend towards significance for mealtime condition (chi-square 9.8000, D.F. 4, P = .051).

Table 79

Inappropriate Behaviour - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Controls T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	0.64 (1.2)	3.3 (5.2)	10.9 (21.5)	9.6 (17.4)	14.3 (20.1)
Median	0	0.5	1.5	4	3
Range	0-3	0-16	0-76	0-62	0-44
Unstructured					
Mean	24.1(33.0)	26.3 (29.5)	23.0 (29.8)	16.0 (26.9)	30.5 (38.6)
Median	8	19	3	4.5	6
Range	0-81	0-74	0-88	0-86	0-85
Mealtimes					
Mean	12.3 (21.5)	21.5 (33.9)	10.7 (15.1)	8.0 (7.7)	18.1 (24.2)
Median	0	2	1	0.5	2
Range	0-76	0-96	0-70	0-70	0-67
TOTAL					
Mean	21.1 (30.9)	21.7 (26.8)	20.8 (25.4)	13.9 (21.4)	29.1 (35.2)
Median	3.5	13.5	5	3.5	5
Range	0-80	0-87	0-72	0-61	0-78

Summary of Results

While there were some small changes in resident behaviour over the different assessment phases these did not reach statistical significance. The experimental hypothesis was therefore supported.

Of some interest is the difference between settings in the hospital in relation to the percentage time residents engaged in appropriate, inappropriate or neutral behaviours.

In unstructured settings residents engaged in low levels of appropriate behaviour and higher levels of neutral behaviour. While in structured settings the situation was reversed and saw residents engaged in high levels of appropriate behaviour and low levels of neutral behaviour. Inappropriate behaviour also varied according to the setting with more inappropriate behaviour occurring in

unstructured as opposed to structured settings although the rates were very low. Mealtimes, which by definition are 'purposeful' saw slightly lower levels of appropriate behaviour than structured settings but higher than unstructured settings.

It would therefore seem that residents in hospital are engaged appropriately more often when in a setting which is task focused than when left to their own devices.

Staff Attention

The experimental hypothesis was that there would be no change in the amount of staff interaction for residents remaining in hospital.

Staff Positive Attention

Comparison of the total group average scores as displayed in Table 80 show little variability in the percentage of time staff spent interacting with residents in hospital over T1 - T5. The percentage time at baseline was 5.4% (median 2 %) decreasing a little to 3.5% (median 1%) by 24 months. The Friedman test did not reveal significance (chi-square 2.8222, D.F. 4, P =.59). Across all assessment phases staff engaged in more 'closed' interactions than 'open' interactions. At baseline and 24 months closed interaction accounted for 4.5% and 2.97% of the time respectively while open interaction accounted for only 0.9% of the time at baseline and 0.7% at 24 months. Individual variations between people ranged from 0% - 58%.

There was no significant difference as examined by the Friedman test for open interaction (chi-square 4.3333, D.F. 4, P =.36) or for closed interaction (chi-square 1.2889, D.F. 4, P =.86).

Table 80

Staff Attention - Total Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Controls T1 - T5

Staff Behaviour	Baseline	6 months	12 months	18 months	24 months
Staff Positive (Open)					
Mean	0.9 (1.6)	1.0 (1.3)	0.8 (1.6)	1.7 (1.8)	0.7 (1.1)
Median	0.5	1.0	0	1.0	0
Range	0-6	0-5	0-6	0-7	0-3
Staff Positive (Closed)					
Mean	4.5 (12.0)	2.7 (4.1)	1.8 (2.2)	2.7 (3.0)	2.9 (4.1)
Median	1	1	1	1.5	2.0
Range	0-52	0-16	0-9	0-12	0-13
Staff Total					
Mean	5.4 (13.2	3.7 (4.2)	2.5 (2.9)	4.4 (3.4)	3.5 (5.1)
Median	2	2	1	3.5	1
Range	0-58	0-16	1-12	0-14	0-16

Setting Conditions

Table 81 displays scores for setting conditions. Structured settings accounted for most staff interaction across T1 - T5 with staff spending 9.8% (median 3%) of time at baseline and 11.5% (median 2%) of the time at 24 months interacting with residents. Staff engaged in more closed interaction in this setting than open interaction. The lowest rate of staff interaction was found for unstructured settings with a mean percentage time of 1.5% (median 1%) at baseline and 1.8% (median 1%) at 24 months .

Table 81

Staff Attention: Structured, Unstructured, Mealtimes - Percentage Time
Means, Medians and Standard Deviations (in parenthesis)
Controls T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Staff Positive (Open)					
Mean	2.7(4.1)	1.0 (1.0)	2.2 (4.8)	2.7 (2.6)	2.3 (3.9)
Median	1	1	0	3	0.5
Range	0-14	0-3	0-15	0-9	0-10
Staff Positive (Closed)					
Mean	6.9 (15.5)	7.3 (12.6)	2.6 (5.1)	6.2 (7.9)	9.2 (19.1)
Median	1	1	1	3.5	1.5
Range	0-52	0-40	0-18	0-29	0-48
Staff Total					
Mean	9.8 (17.8)	8.3 (13.1)	4.7 (8.3)	9.0 (9.4)	11.5 (22.9)
Median	3	2	2	5	2
Range	0-58	0-41	0-27	0-34	0-58
Unstructured					
Staff Positive (Open)					
Mean	0.4 (0.6)	1.1 (2.4)	0.3 (0.6)	1.4 (2.3)	0.3 (0.7)
Median	0	0	0	0.5	0
Range	0-2	0-10	0-2	0-6	0-2
Staff Positive (Closed)					
Mean	1.2 (1.3)	1.2 (1.3)	1.2 (1.5)	1.3 (1.5)	1.5 (2.1)
Median	1	1	1	1	0
Range	0-4	0-5	0-5	0-5	0-5
Staff Total					
Mean	1.5 (1.5)	2.3 (3.1)	1.5 (1.5)	2.9 (2.9)	1.8 (2.5)
Median	1	1.5	1	2.5	1.0
Range	0-5	0-13	0-5	0-8	0-7
Mealtimes					
Staff Positive (Open)					
Mean	0.3 (0.5)	0.6 (0.9)	0.8 (1.5)	0.9 (1.1)	0.7 (0.7)
Median	0	0	0	1	1
Range	0-1	0-3	0-5	0-3	0-2
Staff Positive (Closed)					
Mean	2.8 (2.4)	1.2 (1.7)	1.1 (1.4)	2.1 (3.3)	1.5 (2.1)
Median	2	1	1	2.5	2
Range	0-9	0-7	0-5	0-11	0-6
Staff Total					
Mean	3.1 (2.6)	1.8 (2.0)	1.9 (2.0)	3.0 (3.5)	2.2 (2.0)
Median	2	1	1	2.5	2
Range	0-10	0-7	0-7	0-11	0-6

Mealtimes saw very little contact from staff, with mean percentage time at baseline 3.1% (median 2%) and at 24 months 2.2% (median 2%) with less than 1% of interaction during mealtimes being 'open'.

While a little variability in average scores is apparent across T1- T5, Friedman does not reveal significance for any of the setting conditions, structured (chi-square 3.2000, D.F. 4, P =.52); unstructured (chi-square 4.0750, D.F. 4, P =.40) or mealtime (chi-square 1.4000, D.F. 4, P =.84).

Summary of Results

The percentage of time staff spent interacting with residents in the hospital setting did not change over the period of time under investigation. The experimental hypothesis is therefore supported. When staff interacted with residents in the hospital setting it tended to be in structured settings and the type of interaction was more often 'closed' i.e. not allowing for a response. Very low rates of interaction were observed in unstructured settings and during mealtimes.

Resident : Resident Interaction

The experimental hypothesis was that there would be no change in the amount of resident-resident interaction for people remaining in hospital.

The percentage of time residents in hospital spent interacting with each other was very low across T1 - T5. Total mean percentage time, as displayed in Table 82 at baseline was 0.7% (range 0 - 13) and at 24 months 0.6%
The Friedman test did not show significance (chi-square 2.5111, D.F. 4, P = .64) for all conditions. No significance was found for structured (chi-square 1.8400, D.F. 4, P =.78); unstructured (chi-square 2.9500, D.F. 4, P =.57) and mealtime (chi-square 4.2500, D.F. 4, P =.37).

Table 82

Resident-Resident Interaction - Percentage Time
Means, Medians and Standard Deviations (In parenthesis)
Controls T1 - T5

Setting Conditions	Baseline	6 months	12 months	18 months	24 months
Structured					
Mean	0.2 (0.4)	0.4 (0.9)	0.4 (0.9)	0.5 (1.1)	0.0 (0.0)
Median	0	0	0	0	0
Range	0-1	0-3	0-3	0-4	0
Unstructured					
Mean	1.2 (2.1)	2.5 (5.2)	1.2 (2.1)	1.2 (2.6)	1.0 (2.0)
Median	0	0	0	0	0
Range	0-4	0-18	0-7	0-11	0-3
Mealtimes					
Mean	0.4 (0.9)	1.1 (2.2)	0.4 (0.8)	0.5 (1.0)	0.1
Median	0	0	0	0	0
Range	0-3	0-8	0-2	0-4	0-4
TOTAL					
Mean	0.7 (1.1)	1.7 (3.7)	0.8 (1.4)	0.9 (1.6)	0.6 (0.6)
Median	0	0	0	0	0
Range	0-13	0-15	0-3	0-6	0-3

Summary of Results

Results from the analysis support the experimental hypothesis that the rate of resident-resident interaction does not change for people remaining in hospital. However, the overall percentage time residents interacted with each other across T1 - T5 was less than 1%. Even at mealtimes where some interaction might be expected the rate was less than 0.5%. Structured settings saw similar low levels with a slight increase in unstructured settings. It is difficult to draw any firm conclusion from the data other than the rates of interaction between residents in hospital were almost non-existent.

111 COMPARISONS BETWEEN MOVERS AND STAYERS

The earlier sections of this chapter examined, separately, the effects of relocation and the effects of remaining in hospital on levels of resident engagement and rates of interaction between care staff and people with a learning disability up to a 24 month follow up. This section examines any differences between the movers (subjects) and the stayers (controls) on the variables under investigation. Data for subjects and controls are examined at each assessment time and a comparison between the two groups made.

Resident Behaviour

1) Appropriate Behaviour

The results of the between group analysis over T1 - T5 for appropriate behaviour are shown in Table 83

No differences between the groups with regard to the overall time spent engaged (i.e. for all conditions) in appropriate behaviour were found at any of the assessment times. While the mean score for subjects increased a little between baseline and subsequent assessments relative to the controls (see Figure 19) statistical analysis reveals no significant differences.

Table 83

Appropriate Behaviour
Differences between Subjects and Controls T1 - T5

Setting Conditions		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Structured						
	χs	58.0	50.2	50.8	63.1	62.3
	χc	75.0	84.5	70	78.5	76.0
	Z	-1.979	-2.559	-.511	-.539	-.321
	P	**.048***	**.010****	**.609**	**.590**	**.748**
Unstructured						
	χs	16.3	37.3	40.0	45.5	36.5
	χc	13.5	16.6	22.3	30.9	21.8
	Z	-.730	-3.036	-2.463	-.990	-1.596
	P	**.466**	**.002****	**.014***	**.322**	**.110**
Mealtimes						
	χs	62.6	76.2	82.0	86.0	76.3
	χc	54.5	52.9	55.0	73.9	60.0
	Z	-1.118	-2.628	-2.409	-1.415	-1.150
	P	**.246**	**.009****	**.016***	**.157**	**.250**
Total (all conditions)						
	χs	35.3	48.6	50.3	57.0	46.1
	χc	36.0	36.2	38.4	49.1	37.8
	Z	-.026	-1.776	-1.657	-.697	-1.255
	P	**.976**	**.076**	**.097**	**.486**	**.209**

χs mean score subjects
χc mean score controls
* .05 significance level
** .01 significance level
*** .001 significance level

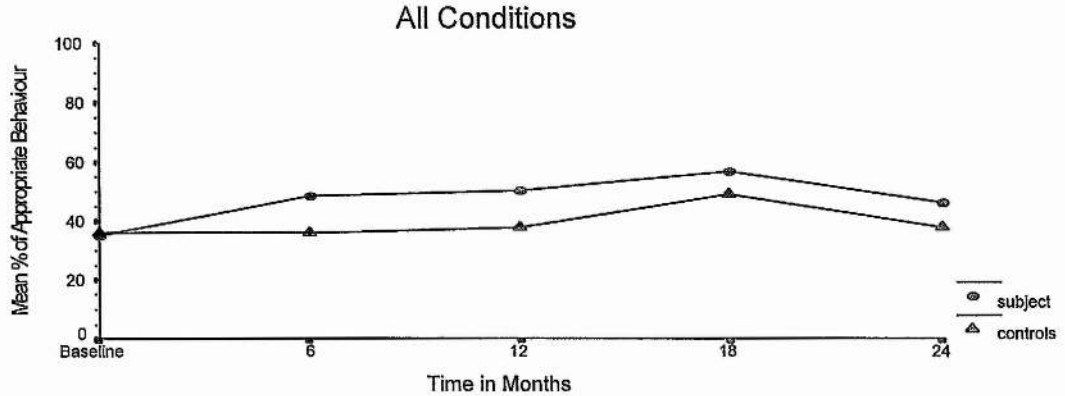


Figure 19 : Mean percentage time for appropriate resident behaviour - all conditions Subject and Control groups (T1-T5)

Setting Conditions

Figures 20 to 22 show the total mean percentage time for subject and controls for the different conditions. For structured settings the control group engaged in higher levels of appropriate behaviour over T1 - T5 compared to the subject group. However, statistical analysis reveals significant differences only for baseline (P<.05) and 6 months (P <.01) with no differences apparent at 12, 18 and 24 months.

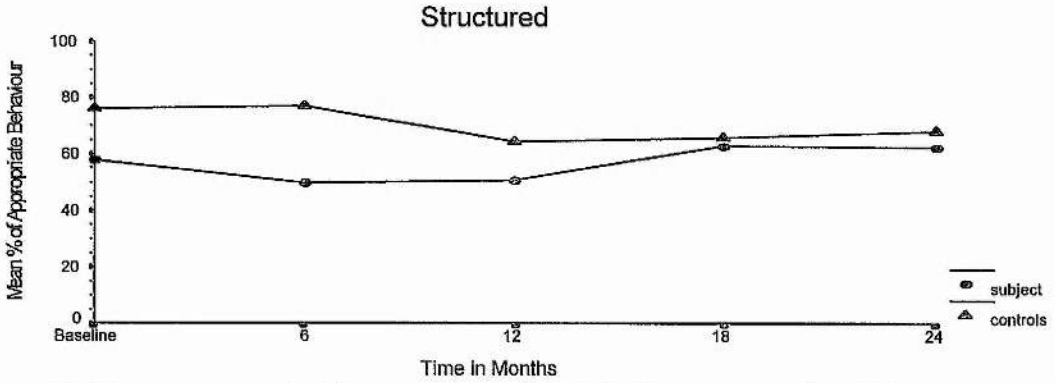


Figure 20 : Mean percentage time for appropriate resident behaviour - structured condition Subject and Control groups (T1-T5)

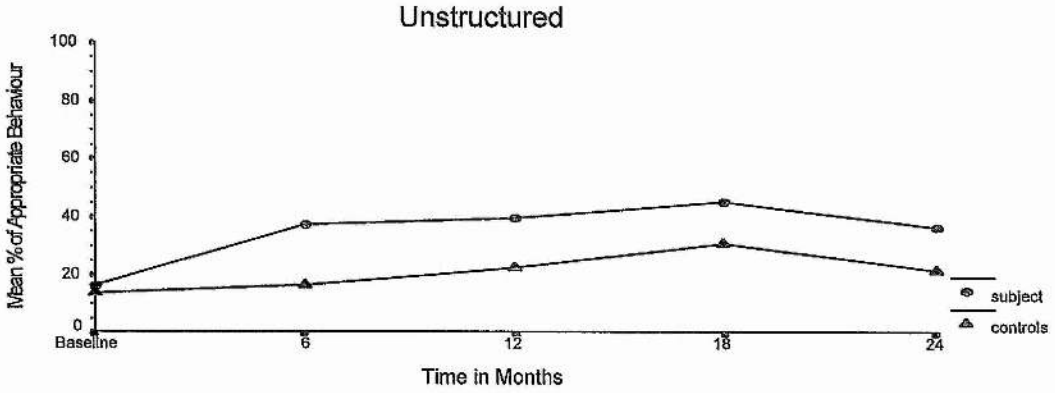


Figure 21: Mean percentage time for appropriate resident behaviour - unstructured condition Subject and Control groups (T1-T5)

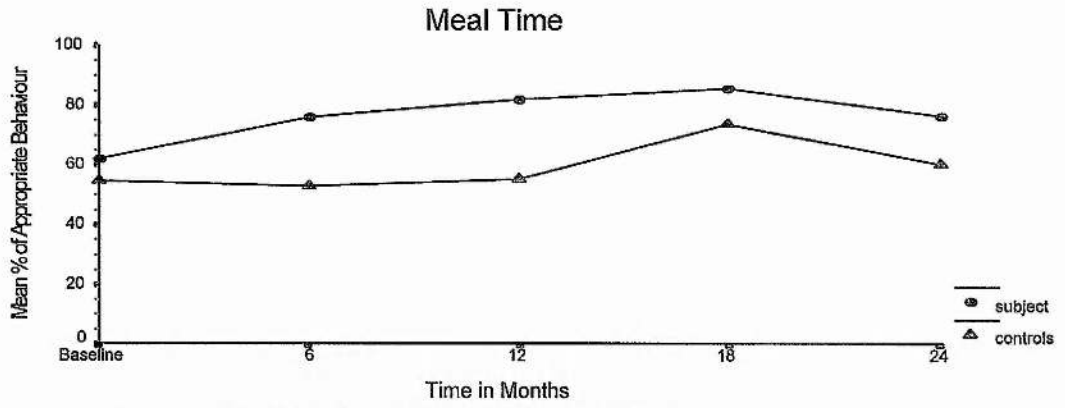


Figure 22: Mean percentage time for appropriate resident behaviour - mealtime condition Subject and Control groups (T1-T5)

In unstructured settings and during mealtimes subjects spent more time engaged in appropriate behaviour from 6 months compared to the control group with significant differences found at 6 months ($P < .01$) and 12 months ($P < .05$) only. These differences between the groups were not maintained at 18 and 24 months.

2) Neutral Behaviour

The results of the between group analysis over T1 - T5 for neutral behaviour are shown in Table 84.

Over all conditions no significant differences emerge between subjects and controls across all assessments. There is a tendency for neutral behaviour to decrease over T1 - T4 for both groups (see Figure 23) with a slight increase for subjects only at 24 months.

Table 84

Neutral Behaviour
Differences between Subjects and Controls T1 - T5

Setting Conditions		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Structured						
	χs	38.1	36.6	28.3	31.2	36.9
	χc	21.6	18.8	22.7	24.3	16.0
	Z	-2.002	-2.165	-.325	-.425	-1.456
	P	**.045***	**.030***	**.745**	**.885**	**.450**
Unstructured						
	χs	60.2	43.5	37.3	38.8	44.1
	χc	59.8	53.2	48.1	44.3	38.2
	Z	-.041	-1.301	-1.626	-.494	.532
	P	**.967**	**.193**	**.104**	**.621**	**.595**
Mealtimes						
	χs	27.3	18.4	9.2	9.9	10.9
	χc	32.9	24.0	25.8	18.1	20.4
	Z	-1.685	-1.073	-2.387	-1.248	-1.842
	P	**.092**	**.283**	**.017***	**.212**	**.065**
Total (all conditions)						
	χs	45.1	37.3	29.1	30.9	38.1
	χc	41.1	39.6	36.7	32.7	27.6
	Z	- .841	-.355	-1.429	-.382	-1.027
	P	**.400**	**.723**	**.153**	**.702**	**.304**

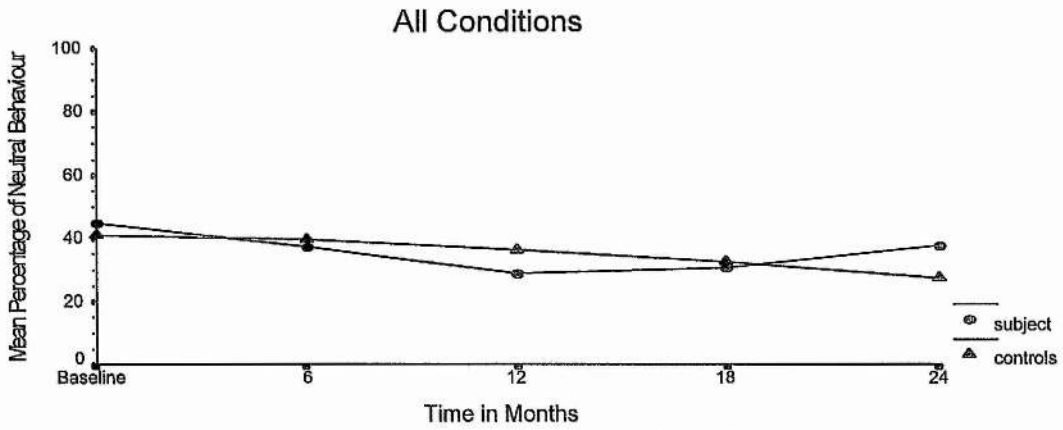


Figure 23: Mean percentage time for neutral resident behaviour - all conditions
Subject and Control groups (T1-T5)

Setting Conditions

Figures 24 - 26 show the mean percentage time for neutral behaviour for the three setting conditions.

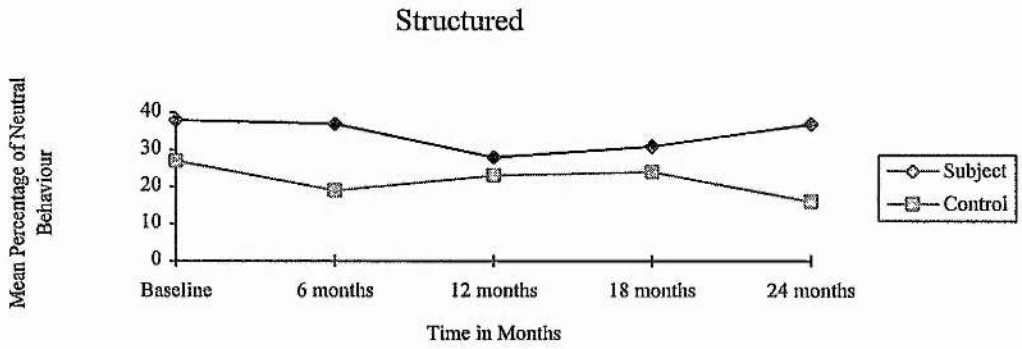


Figure 24 : Mean percentage time for neutral resident behaviour - structured condition Subject and Control groups (T1-T5)

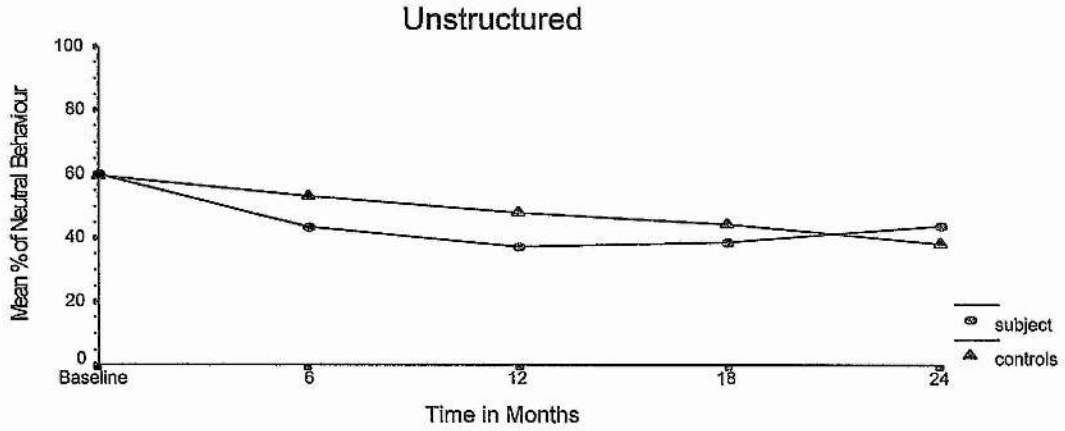


Figure 25: Mean percentage time for neutral resident behaviour - unstructured condition Subject and Control groups (T1-T5)

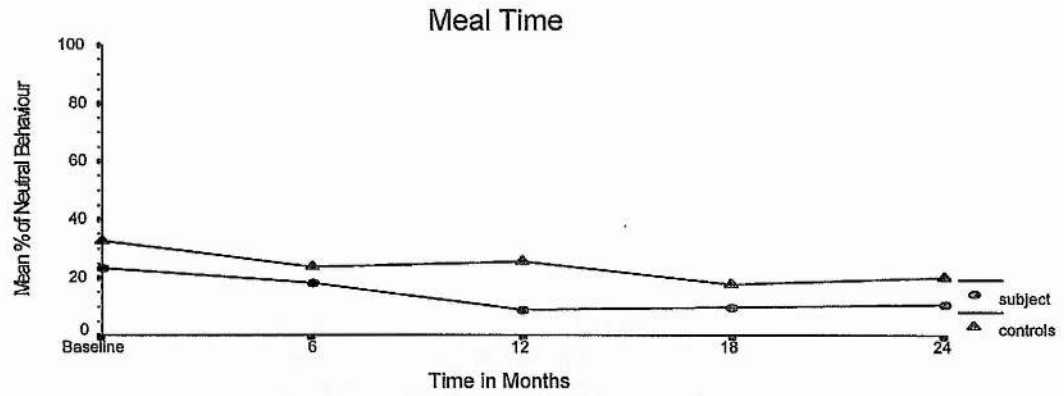


Figure 26: Mean percentage time for neutral resident behaviour - mealtime condition Subject and Control groups (T1-T5)

In structured settings subjects were observed engaging in neutral behaviour for a higher percentage of time across T1 - T5 than the control group. Significant differences were found only at baseline and 6 months ($P < .05$).

In unstructured settings the percentage of time both groups engaged in neutral behaviour shows a tendency to decrease over T1 - T5. No significant differences between the groups emerged.

During mealtimes, controls engaged in higher levels of neutral behaviour but a significant difference between the groups was found only at 12 months ($P < .05$). There was a tendency for neutral behaviour to decrease for both groups over time.

3) Inappropriate Behaviour

The results of the between group analysis over T1 - T5 for inappropriate behaviour are shown in Table 85.

Table 85

Inappropriate Behaviour
Differences between Subject and Controls T1 - T5

Setting Conditions		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Structured						
	χs	3.0	8.1	19.6	7.3	0.83
	χc	0.6	3.3	10.9	9.6	14.3
	Z	-.982	-.231	-.827	-.145	-1.456
	P	**.326**	**.817**	**.408**	**.885**	**.450**
Unstructured						
	χs	18.3	14.8	19.5	13.5	16.3
	χc	24.1	26.3	23.0	16.0	30.5
	Z	-.237	-1.231	-.123	-.614	-1.235
	P	**.813**	**.218**	**.902**	**.539**	**.217**
Mealtimes						
	χs	14.3	5.3	8.7	3.7	9.0
	χc	12.3	21.5	10.7	8.0	18.1
	Z	-.496	-.237	-.209	-1.246	-1.123
	P	**.624**	**.813**	**.834**	**.213**	**.262**
Total (all conditions)						
	χs	15.4	10.1	16.9	11.5	14.4
	χc	21.1	21.7	20.8	13.9	29.1
	Z	-.106	-1.531	.000	-.658	-1.225
	P	**.915**	**.126**	**1.000**	**.511**	**.220**

Inappropriate behaviour changes little for both groups over T1 - T4 with a slight increase for the control group at 24 months. Statistical analysis reveals no significant differences between groups for all assessments

Figure 27 shows the mean percentage time for inappropriate behaviour for subjects and controls over T1 - T5 for all conditions.

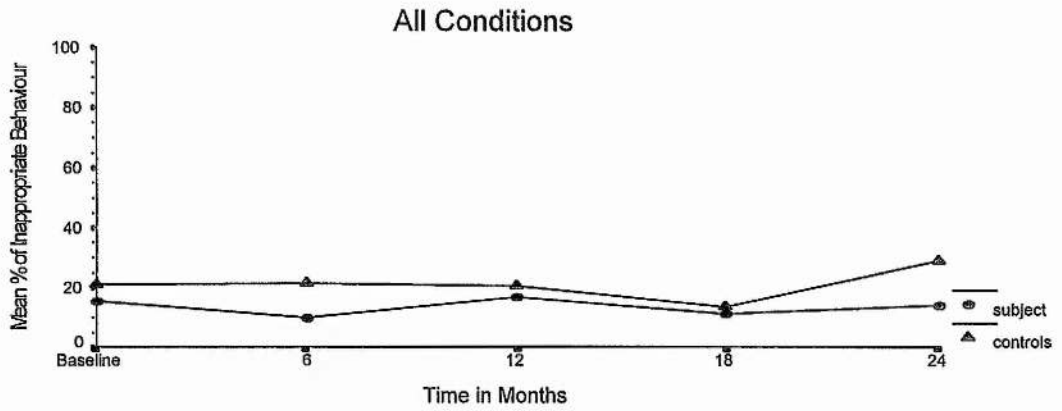


Figure 27: Mean percentage time for inappropriate resident behaviour - all conditions Subject and Control groups (T1-T5)

Setting Conditions

Figures 28 to 30 show mean percentage time for inappropriate behaviour for the three setting conditions. No significant differences were found. Inappropriate behaviour occurred at a low level in structured settings for both groups although some variability was apparent across assessment phases.

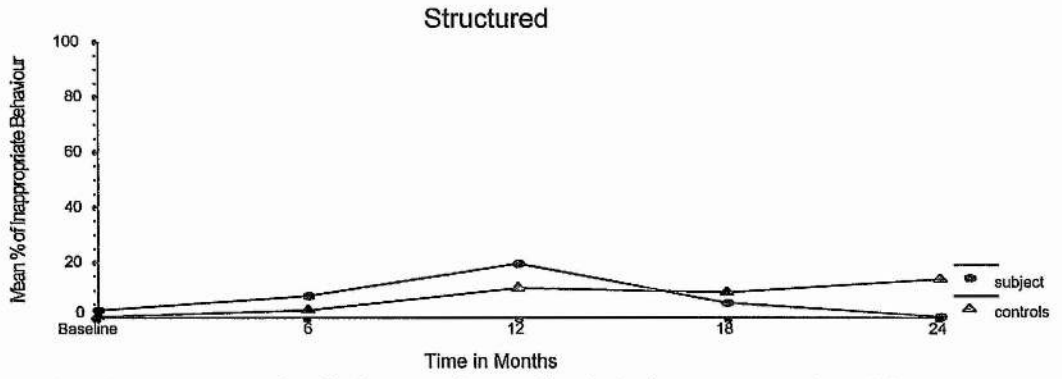
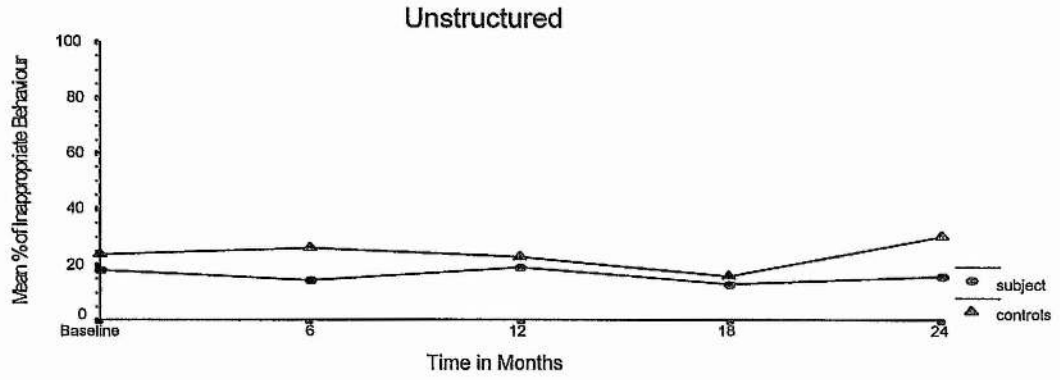


Figure 28: Mean percentage time for inappropriate resident behaviour - structured condition Subject and Control groups (T1-T5)



\Figure 29: Mean percentage time for inappropriate resident behaviour - unstructured condition Subject and Control groups (T1-T5)

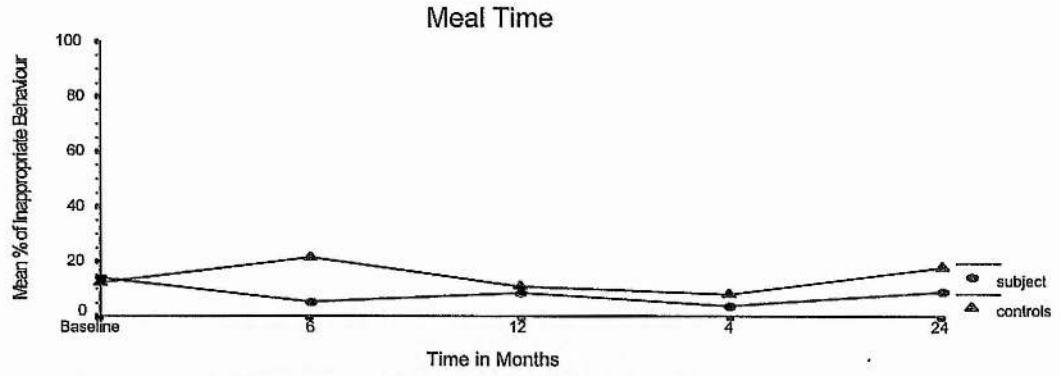


Figure 30: Mean percentage time for inappropriate resident behaviour -mealtime condition Subject and Control groups (T1-T5)

Similar rates of inappropriate behaviour were observed in unstructured settings for both groups with the control group showing an increase at 24 months.

Relatively low levels of inappropriate behaviour were observed during mealtimes for both groups.

Summary of Results

Comparing subject and control groups across T1 - T5 revealed few significant differences between the groups. While no differences were found for the overall percentage of time both groups were observed engaging in appropriate, neutral and inappropriate behaviour, some differences between settings emerged for appropriate and neutral behaviour. For the subjects group, following discharge

to the community, levels of appropriate behaviour were higher than the control group at 6 months and 12 months for unstructured and mealtime settings. These differences between the groups were not maintained at the 18 and 24 month follow up.

For structured settings a difference between the groups on appropriate behaviour was evident at baseline, but not at the more stringent .01 level of significance. This difference continued at 6 months but was not evident thereafter.

In relation to neutral behaviour only one significant difference emerged at T3 for the mealtime setting. Again this was not at the more stringent .01 level of significance and could be interpreted as potential rogue result.

In conclusion, while any changes for the subject group relative to the control group were generally in the predicted direction - overall there are insufficient differences to effectively discriminate between the behaviour of people remaining in hospital to the behaviour of those discharged to the community.

Staff Attention

Table 86 displays the results of the between group analyses over T1 - T5 for staff attention.

Table 86

Staff Attention - Total, Total Open - Total Closed
Differences between Subjects and Controls T1 - T5

Staff Behaviour	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Staff Positive (Open)					
χs	0.87	6.3	4.2	4.5	5.3
χc	0.9	1.0	0.8	1.7	0.7
Z	-.043	3.261	-4.025	-3.047	-3.209
P	**.965**	**.001*** **	**.000*** **	**.002** **	**.001*** **
Staff Positive (Closed)					
χs	1.8	3.0	7.3	5.6	6.3
χc	4.5	2.7	1.8	2.7	2.9
Z	-.676	1.314	-3.606	-1.254	1.458
P	**.499**	**.189**	**.000*** **	**.210**	**.145**
Staff Total					
χs	2.7	9.2	11.5	10.2	11.5
χc	5.4	3.7	2.5	4.4	3.5
Z	.253	.2.611	-3.962	-2.574	-2.631
P	**.800**	**.009** **	**.000*** **	**.010** **	**.009** **

Overall all conditions significant differences were found between the groups at 6, 12, 18 and 24 months ($P < .01$). The percentage of time staff interacted with residents in the hospital setting remained low and showed minimal change over time while for the subject group there was an immediate increase at 6 months which was maintained thereafter. Figure 31 shows the total mean percentage time for staff (positive) interaction for both groups.

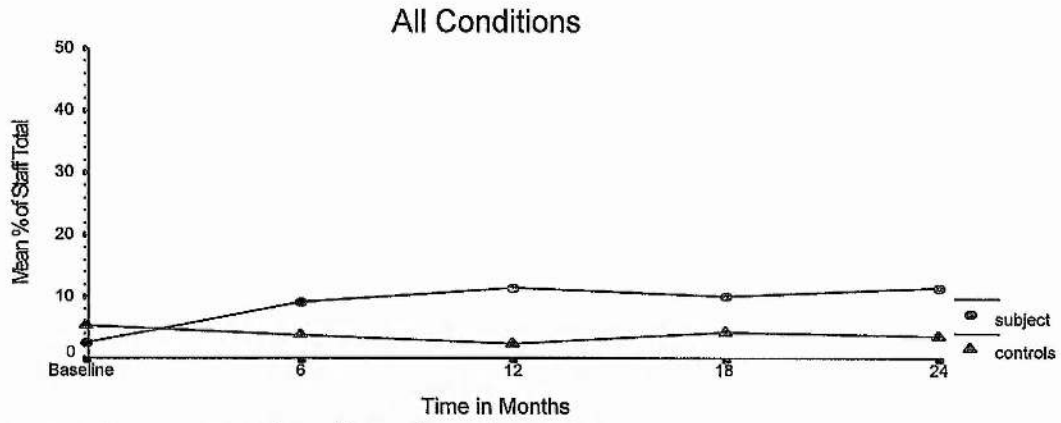


Figure 31: Mean percentage for staff attention - all conditions
Subject and Control groups (T1-T5)

For staff open interaction there was a consistent difference between subject and control groups from 6 months, in favour of the subject group ($P < .01$). There was little difference between the groups in relation to staff closed interaction with a significant result only at 12 months ($P < .01$).

Setting Conditions

The results of the between group analyses over T1 - T5 for staff attention for the three setting conditions are shown in Table 87

Table 87

Staff Attention: Structured, Unstructured, Mealtimes
Differences between Subjects and Controls T1 - T5

Setting Conditions	Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Structured					
Staff Positive (Open)					
χs	2.3	5.9	3.0	4.8	5.8
χc	2.7	1.0	2.2	2.7	2.3
Z	-.779	-1.758	-1.042	-1.470	.749
P	**.436**	**.079**	**.297**	**.142**	**.454**
Staff Positive (Closed					
χs	3.8	3.5	6.6	5.5	6.0
χc	6.9	7.3	2.6	6.2	9.2
Z	.000	-.237	-1.467	-1.201	-.500
P	**1.000**	**.813**	**.142**	**.230**	**.617**
Staff Total					
χs	5.8	9.3	9.6	10.3	11.8
χc	9.8	8.3	4.7	9.0	11.5
Z	-.699	-.653	-1.055	-.227	-.903
P	**.485**	**.541**	**.292**	**.820**	**.366**
Unstructured					
Staff Positive (Open)					
χs	0.6	6.8	5.6	5.2	4.7
χc	0.4	1.1	0.3	1.4	0.3
Z	-.099	-2.888	-4.947	-2.756	-2.719
P	**.921**	**.004****	**.000*****	**.006****	**.007****
Staff Positive Closed					
χs	0.71	2.3	6.2	5.4	4.6
χc	1.2	1.2	1.2	1.3	1.5
Z	-.961	-1.362	-4.015	-.2407	-1.259
P	**.337**	**.173**	**.000****	**.016***	**.208**
Staff Total					
χs	1.3	9.0	11.8	10.5	9.4
χc	1.5	2.3	1.5	2.9	1.8
Z	-.727	-2.873	-4.520	-3.121	-2.161
P	**.467**	**.004****	**.000****	**.002****	**.031***
Mealtimes					
Staff Positive (Open)					
χs	0.7	4.6	3.6	2.4	3.1
χc	0.3	0.6	0.8	0.9	0.7
Z	-1.036	-1.573	-1.968	-1.200	-.567
P	**.300**	**.116**	**.049***	**.230**	**.571**
Staff Positive (Closed)					
χs	1.9	3.7	9.6	5.4	13.0
χc	2.8	1.2	1.1	2.1	1.5
Z	-2.272	-.206	-2.391	-.431	-.029
P	**.025***	**.837**	**.017***	**.667**	**.979**
Staff Total					
χs	2.5	8.3	13.2	7.7	16.1
χc	3.1	1.8	1.9	3.0	2.2
Z	-1.512	-1.082	-2.345	-1.054	-1.042
P	**.131**	**.279**	**.019***	**.292**	**.297**

For structured settings no significant differences were found.

In unstructured settings the percentage time staff interacted with residents was significantly higher for the subject group at 6,12, 18 ($P < .01$) and 24 months ($P < .05$). There was a consistent difference between the groups for open interaction from 6 months ($P < .01$) and more variable differences for closed interaction with a significant result found at 12 months ($P < .01$) and 18 months ($P < .05$) only.

For mealtimes a significant difference between the groups is found only at 12 months ($P < .05$), for both open and closed interaction and for closed interaction a difference was apparent at baseline only ($P < .05$).

Figures 32 to 34 show mean percentage time for staff interaction for the three setting conditions.

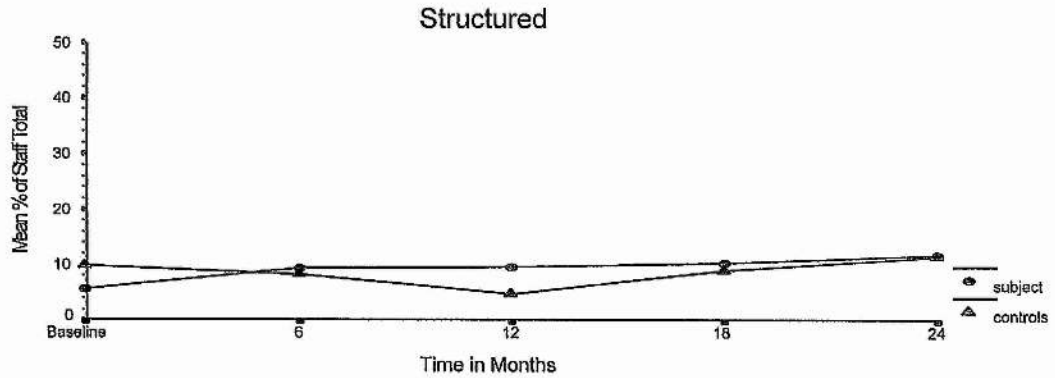


Figure 32: Mean percentage time for staff attention (total)- structured condition
Subject and Control groups (T1-T5)

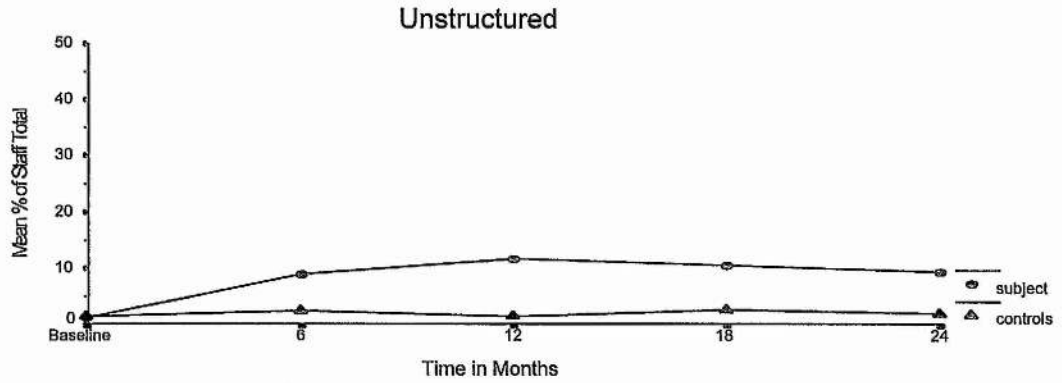


Figure 33 : Mean percentage time for staff attention (total) - unstructured condition
Subject and Control groups (T1-T5)

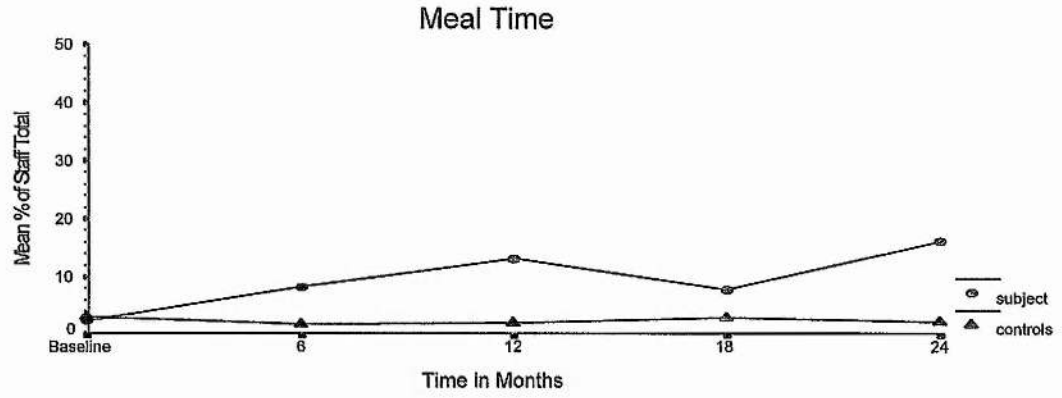


Figure 34 : Mean percentage time for staff attention (total) - mealtime condition
Subject and Control groups (T1-T5)

Summary of Results

The percentage of time staff spent interacting with residents increased significantly for people moving to the community relative to those people remaining in hospital. The differences reflected changes in open interaction with little change in time spent by staff in closed interaction.

An examination of setting conditions revealed differences between the groups in unstructured settings following discharge to the community for the subject group. There were no differences between the groups for structured settings and minimal change during mealtimes.

The measure of staff behaviour in unstructured settings effectively discriminated between the two groups particularly in relation to open interaction..

Resident - Resident (Interaction)

Table 88 presents results over T1 - T5 for resident - resident interaction. No significant differences were found.

Table 88

Resident : Resident Interaction
Differences between Subjects and Controls T1 - T5

Setting Conditions		Baseline (T1)	6 months (T2)	12 months (T3)	18 months (T4)	24 months (T5)
Structured						
	χs	1.1	1.0	1.2	0.8	0.3
	χc	0.2	0.4	0.4	0.5	0.0
	Z	-.809	-.271	-.985	-.358	-1.000
	P	**.419**	**.786**	**.325**	**.720**	**.317**
Unstructured						
	χs	1.1	1.2	1.7	3.5	4.5
	χc	1.2	2.5	1.2	1.2	1.0
	Z	-.789	-.118	-.388	-.545	-.041
	P	**.430**	**.906**	**.698**	**.586**	**.967**
Mealtimes						
	χs	3.0	2.8	2.8	0.5	2.5
	χc	0.4	1.1	0.4	0.5	0.1
	Z	-1.685	-.264	-1.684	-.029	-1.842
	P	**.092**	**.792**	**.092**	**.977**	**.065**
Total (all conditions)						
	χs	1.3	1.3	2.1	0.9	2.2
	χc	0.7	1.7	0.8	0.8	0.6
	Z	-.458	-.044	-1.668	-.303	.776
	P	**.647**	**.965**	**.095**	**.762**	**.438**

Figure 35 shows the total mean percentage time for resident - resident interactions for subject and control groups over T1 - T5.

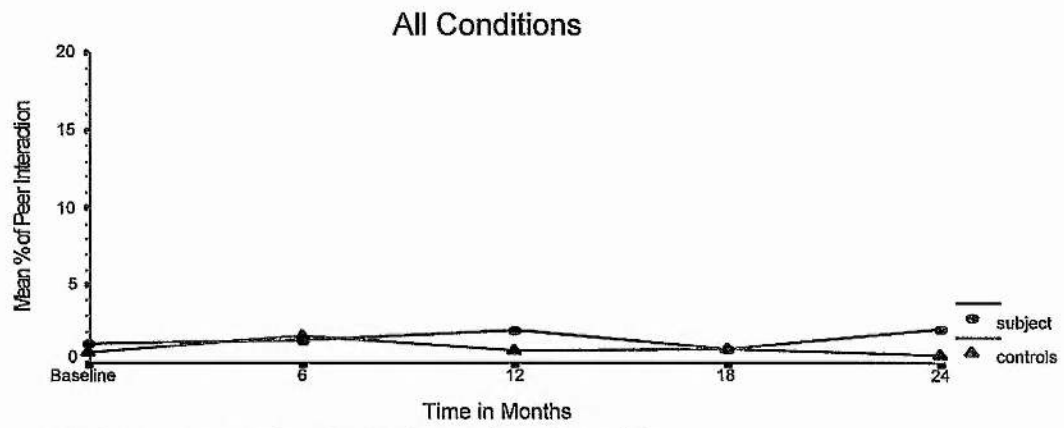


Figure 35: Mean percentage time for peer interaction - all conditions
Subject and Control groups (T1-T5)

The time residents interacted with each other in both hospital and community settings was extremely low across all assessment phases and setting conditions with no change for those people moving to community settings.

Summary of Results

The measure of resident - resident behaviour yielded similar but very low rates of peer interaction for both subject and control groups. This measure did not discriminate between people living in hospital and those people living in community settings. No change for both groups was found over the period of time under investigation i.e. up to a 24 month follow up. Given the low rates of interaction it was difficult to draw any conclusions in relation to the different setting conditions.

I V RELATIONSHIP BETWEEN STAFF BEHAVIOURS AND RESIDENT BEHAVIOURS

No specific hypotheses were put forward with regard to the relationship between staff behaviour and resident behaviour. It was examined for both people living in hospital and for those discharged to community residences under two conditions, unstructured and mealtimes. Data from observations of 18 subjects and 18 controls were included.

An analysis of behavioural sequences was conducted for 18 possible pairings of resident and staff behaviours. However, because of the relatively low levels of staff interaction in some settings staff 'open' and staff 'closed' interactions were combined as a total staff positive category. Staff negative interaction was excluded as virtually none was observed throughout the course of the study.

As a result 6 parings of resident and staff behaviours were analysed for both unstructured settings and mealtimes in order to examine the likelihood of the different categories of resident behaviour attracting staff attention and the likelihood of the different categories of resident behaviour resulting from staff attention.

Two questions were examined in relation to each category of resident behaviour:-

1. What was the probability of resident appropriate/inappropriate/neutral behaviour attracting staff attention?
2. What was the probability of staff attention being associated with resident appropriate/inappropriate/neutral behaviour?

Correlational analysis was conducted using the Spearman's Correlation Co-efficient (Siegal, 1956).

Resident Appropriate Behaviour and Staff Interaction

1. What was the probability of resident appropriate behaviour attracting (i.e. leading to) staff attention in unstructured settings or during mealtimes?

Table 89 shows the correlations between resident appropriate behaviour and staff attention for subjects and controls across T1-T5 for unstructured settings and mealtimes.

TABLE 89

Resident Appropriate Behaviour leading to Staff Attention, Unstructured & Mealtimes - Correlation Coefficients and Significance Levels
Subjects & Controls (T1-T5)

	SUBJECTS					CONTROLS				
	Unstructured			Mealtimes		Unstructured			Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	18	0.306	N.S.	0.135	NS	18	0.696	0.01**	0.157	N.S.
6 months	18	0.268	N.S.	-0.069	N.S.	18	0.789	0.01**	0.485	0.05*
12 months	18	0.142	N.S.	-0.441	N.S.	18	0.598	0.02*	0.351	N.S.
18 months	11	0.63	N.S.	-0.698	.05(-ve)	18	0.262	N.S.	-0.057	N.S.
24 months	11	-0.045	N.S.	-0.299	N.S.	9	0.310	N.S.	-0.236	N.S.

N.S. Not Significant
* <.05
** <.01

In unstructured settings, for the subject group, no significant relationship was found between resident appropriate behaviour and staff attention.

For the control group results give a mixed picture. A significant relationship between resident appropriate behaviour and staff attention is achieved at Baseline, 6 months and 12 months but not for subsequent assessments.

During mealtimes for subjects, only one assessment (18 months) points to a significant negative relationship. For the controls the results at 6 months point to a significant relationships between resident appropriate behaviour and staff attention, but only at the .05 significance level.

2. What was the probability of staff attention being associated with resident appropriate behaviour?

Table 90 shows the correlation coefficients and significance levels for staff attention and resident appropriate behaviour for unstructured settings and mealtimes.

In unstructured settings, for subjects, there was a significant relationship between staff attention and resident appropriate behaviour at 6 months (P <.01) with significance at the less stringent level found at 24 months (P <.05).

For controls a significant relationship was found at 6 months (P <.01) and 18 months (P <.01) with a tendency towards significance at baseline (P <.05).

TABLE 90

Resident Appropriate Behaviour following Staff Attention, Unstructured & Mealtimes - Correlation Coefficients and Significance Levels
Subjects and Controls T1-T5

	SUBJECTS					CONTROLS				
		Unstructured		Mealtimes			Unstructured		Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	18	0.273	NS	0.6777	.01**	18	0.515	05*	0.478	.05*
6 months	18	0.679	.01**	0.860	.01**	18	0.690	.01**	0.108	N.S.
12 months	18	0.417	N.S.	0.913	.01**	18	0.371	N.S.	0.853	.01**
18 months	11	0.418	N.S.	0.926	.01**	18	0.830	.01**	0.654	.01**
24 months	11	0.738	.05*	0.818	.01**	9	0.667	N.S.	0.913	.01**

N.S. Not significant
* < .05 level
** < .01 level

For mealtimes, for subjects, there is a strong relationship between staff attention and resident appropriate behaviour for all assessments (P<.01). For controls a significant relationship (P <.01) is found at 12 months, 18 months and 24 months with a relationship approaching significance found at baseline (P <.05). No relationship was found for the control group at 6 months.

Summary of Results

Results from a sequential analysis of resident appropriate behaviour and staff attention reveal some mixed findings. Appropriate resident behaviour in unstructured settings did not attract staff positive attention for the subject group in both the hospital and community settings, whereas for the control group, at baseline, 6 months and 12 months there was a tendency for appropriate behaviour to attract staff attention.

For both groups, in unstructured settings, there was a tendency for appropriate resident behaviour to follow positive staff attention - although not all the results reached significance.

During mealtimes there was a trend towards a negative relationship between resident appropriate behaviour and staff attention for the subject group but no significant findings for the control group. For both groups, in both hospital and community settings, appropriate resident behaviour was likely to result from positive staff attention.

So, while the relationship between resident appropriate behaviour and staff attention appears complex the results support the view that when staff interact with residents in a positive way appropriate resident behaviour results.

Resident Inappropriate Behaviour and Staff Attention

1. What was the probability of resident inappropriate behaviour attracting staff attention in unstructured settings, and during mealtimes?

Table 91 shows the correlation coefficients and significance levels for subjects and controls across T1-T5 for unstructured settings and mealtimes.

TABLE 91

Resident Inappropriate Behaviour leading to Staff Attention, Unstructured & Mealtimes - Correlation Co-efficients and Significance Levels
Subjects and Controls T1-T5

	SUBJECTS					CONTROLS				
		Unstructured		Mealtimes			Unstructured		Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	18	0.711	.001**	0.560	0.05*	18	0.680	0.01**	0.80	0.01**
6 months	18	0.548	0.05*	0.350	N.S.	18	0.7727	0.01**	0.529	0.05*
12 months	18	0.853	0.01**	0.825	0.01**	18	0.669	0.01**	0.424	N.S.
18 months	11	0.629	N.S.	0.742	0.05*	18	0.720	0.01**	0.275	N.S.
24 months	11	0.784	0.02*	0.770	0.02*	9	0.842	0.01**	0.86	0.01**

N.S. Not significant
* <.05 level
** <.01 level

For unstructured settings for both subject and control groups a significant relationship was found for resident inappropriate behaviour and staff attention across T1-T5 with results at 6 months and 18 months for the subject group, only, not reaching the .01 significance level. There was a tendency towards significance for both subject and controls for the mealtime condition.

2. What was the probability of staff attention being associated with inappropriate behaviour?

Table 92 shows the correlation coefficients and significance level for staff attention and resident inappropriate behaviour for unstructured settings and mealtimes.

For subjects and controls, in unstructured settings and during mealtimes, results reveal no significant relationship between staff attention and resident inappropriate behaviour across T1-T5.

Table 92

Resident Inappropriate Behaviour following Staff Attention, Unstructured Settings & Mealtimes
-Correlation Coefficients and Significance Levels
Subjects and Controls (T1-T5)

	SUBJECTS					CONTROLS				
	Unstructured			Mealtimes		Unstructured			Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	19	0.543	0.05*	0.349	N.S.	18	-0.007	N.S.	0.446	N.S.
6 months	19	0.456	N.S.>	0.401	N.S.	18	0.117	N.S.	0.208	N.S.
12 months	19	0.231	N.S.	0.464	N.S.	18	0.377	N.S.	-0.106	N.S.
18 months	11	0.127	N.S.		N.S.	18	0.149	N.S.	0.312	N.S.
24 months	11	0.428	N.S.	0.611	N.S.	9	0.530	N.S.	0.322	N.S.

N.S. Not significant

* <.05 level

** <.01 level

Summary of Results

Results from a sequential analysis of resident inappropriate behaviour and staff attention revealed some mixed findings. Inappropriate resident behaviour attracted staff attention in both hospital and community settings, particularly in unstructured settings.

No relationship was found for resident inappropriate behaviour resulting from staff attention. It would therefore appear that when staff attend to resident behaviour it is likely that they will attend to inappropriate behaviour.

Residential Neutral Behaviour and Staff Interaction

1. What was the probability of resident neutral behaviour being attended to by staff?

Table 93 shows the correlation coefficients and significance levels for resident neutral behaviour and staff attention for subjects and controls.
In unstructured settings, for subjects only, a significant relationship was found at 6 months ($P < .01$).

During mealtimes a significant relationship was found for subjects at 18 months and 24 months. For controls at 6 and 18 months a tendency towards significance ($P < .05$) was found between resident neutral behaviour and staff attention.

Table 93

Resident Neutral Behaviour leading to Staff Attention, Unstructured Settings and Mealtimes
Correlation Coefficients and Significance Levels
Subjects and Controls (T1-T5)

	SUBJECTS					CONTROLS				
	Unstructured			Mealtimes		Unstructured			Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	19	0.480	.05*	0.107	N.S.	18	0.012	N.S.	0.425	N.S.
6 months	19	0.627	.01*	0.457	N.S.	18	0.134	N.S.	0.588	.02*
12 months	19	0.295	N.S.	0.379	N.S.	18	0.006	N.S.	0.416	N.S.
18 months	11	0.602	N.S.	0.924	.01**	18	0.270	N.S.	0.594	.02*
24 months	11	0.623	N.S.	0.983	.01**	9	-0.13	N.S.		

N.S. Not significant
* significant .05 level
** significant .01 level

2) What was the probability of staff attention being associated with resident neutral behaviour?

Table 94 shows the correlation coefficients and significance levels for staff attention and resident neutral behaviour.

For unstructured settings, subjects and controls show a tendency for significance but for subjects only T5 (24 months) and for controls T3 (12 months) reaches significance (P <.01).

During mealtimes, for subjects only, a trend towards significance is found with results at T1 (Baseline) reaching significance (P<.01).

Table 94

Resident Neutral Behaviour following Staff Attention, Unstructured Settings and Mealtimes - Correlation Coefficients and Significance Levels
Subjects and Controls (T1-T5)

	SUBJECTS					CONTROLS				
		Unstructured		Mealtimes			Unstructured		Mealtimes	
Assessment	N	r	2 Tailed	r	2 Tailed	N	r	2 Tailed	r	2 Tailed
Baseline	19	0.273	N.S.	0.629	.01**	18	0.389	N.S.	0.125	N.S.
6 months	19	0.519	0.05*	0.478	.05*	18	0.212	N.S.	0,350	N.S.
12 months	19	0.509	.05*	0.325	N.S.	18	0.661	.01**	0.418	N.S.
18 months	11	0.019	N.S.	0.712	.05*	18	0.394	N.S.	0.363	N.S.
24 months	11	0.781	.02	0.582	N.S.	9	0.711	.05*	0.443	N.S.

N.S. Not significant
* significant .05 level
** significant .01 level

Summary of Results

No consistent findings emerge from the analysis regarding the relationship between resident neutral behaviour and staff attention. The results indicate that for subjects, engagement in neutral behaviour was followed by staff attention, particularly in the community during mealtimes but only some of the time, but a less significant relationship was found for unstructured settings. For controls neutral behaviour was followed by staff attention during mealtimes but no relationship was found for unstructured settings. For subjects, neutral behaviour was attended to by staff inconsistently in community settings, whereas, for controls, there is little evidence of staff attending to neutral behaviour. Staff

attention is associated with resident behaviour - to a degree for subjects but less so for controls.

RESIDENT CHARACTERISTICS AND STAFF:RESIDENT INTERACTION

Assessments of adaptive and maladaptive behaviour were considered an appropriate measure of resident ability, and to some extent, challenging behaviour.

A correlational analysis was conducted to examine the relationship between adaptive and maladaptive behaviour and staff:resident interaction. An overall analysis was conducted across T1-T5 but as adaptive and maladaptive behaviour may have fluctuated over T1-T5 the results are presented in Table 95 for each assessment for both subject and control groups.

TABLE 95

Staff Attention (Total) and Adaptive/Maladaptive Behaviour
Correlation Coefficients and Significance Levels (in parentheses)
Subjects and Controls (T1-T5)

	SUBJECTS		CONTROLS	
ASSESSMENT	ABS (PART 1)	ABS (PART 2)	ABS (PART 1)	ABS (PART 2)
Baseline	-.4264 (.042)	.0181 (.935)	-.0616 (.808)	.1350 (.593)
6 months	-.5474 (.007)**	.0975 (.658)	.2140 (.394)	-.3843 (.115)
12 months	-.6605 (.002)**	.1021 (.678)	-.2562 (.305)	.1752 (.487)
18 months	-.3866 (.240)	.0556 (.871)	-.3183 (.198)	.3141 (.204)
24 months	-.4920 (.124)	.1276 (.709)	.1435 (.713)	-.0127 (.974)
ALL ASSESSMENTS	-.3641 (.000)**	-.0047	-.0236 (N.S.)	-.0194

* -.05
** -.01

For subjects, overall, there was a significant inverse relationship between staff : resident interaction and resident ability (r=-3641, P <.01) but not for the control group (r = - 0236). Examining the results from the different assessment phases, for the subject group only two assessments showed significance at 6 months (r = - 0.5474, P<.01) and 12 months (r=-.6605, P<.01). The relationship was a negative one implying that staff:resident interaction was negatively correlated with adaptive behaviour. There was no relationship between resident maladaptive behaviour and staff interaction for subjects (r =.0047) or controls (r =.0194).

STAFF:RESIDENT RATIOS AND PATTERNS OF INTERACTIONS

A Spearman's correlation analysis was employed to examine the relationship between staff:resident ratios and pattern of interactions between staff and residents. No attempt was made to examine staff behaviour in relation to specific resident groupings (e.g. comparing one unit or ward with another) but rather the data generated on the ratio of staff to residents at each observational session, the percentage of time staff interacted with residents for each assessment and for all conditions (i.e. unstructured, structured and mealtime) was used for the analysis.

Table 96 shows the results for staff open, staff closed and staff total interaction over T1 - T5. Very few significant results were found. For subjects there was a tendency towards a negative relationship between staff:resident ratio and staff interaction at baseline (r = .-5038, P <.05) and at 6 months (r = -.4652, P <.05), and for controls a tendency towards a positive relationship at 18 months (r = .5534, P<.05).

Table 96

Staff:Resident Ratio and Staff Attention
Correlation Coefficients and Significance Levels (in parentheses)
Subjects and Controls (T1-T5)

	SUBJECTS			CONTROLS		
ASSESSMENT	STAFF OPEN	STAFF CLOSED	STAFF TOTAL	STAFF OPEN	STAFF CLOSED	STAFF TOTAL
Baseline	-.4453 (0.56)	-.2884 (.231)	-.5083 (.026)*	-.0371 (.891)	-.3673 (.162)	-.2996 (.260)
6 months	-.5612 (.007)**	-.0593 (.793)	-.4652 (.029)*	.1665 (.509)	.1351 (.593)	.1802 (.474)
12 months	-.0314 (.901)	-.2826 (.256)	-.2145 (.393)	.1658 (.525)	-.0391 (.882)	.1473 (.573)
18 months	-.5566 (.075)	-.4289 (.188)	-.3040 (.262)	.5534 (.017)**	-.1524 (.546)	.1814 (.471)
24 months	-.3319 (.383)	-.5021 (.168)	-.2899 (.449)	-.1559 (.712)	-/6261 (.097)	-.6910 (.058)

* - .05
**- .01

If anything, for subjects, the tendency was for staff:resident ratios to be negatively correlated with staff interaction in community settings. Having more staff present did not lead to higher rates of interaction with residents, and if anything, had the opposite effect.

STAFF: RESIDENT RATIOS AND RESIDENT ENGAGEMENT

Table 97 shows results from analysis between resident engagement in appropriate and inappropriate behaviour and staff:resident ratios.

No consistent relationship was found between staff:resident ratio and resident engagement in appropriate or inappropriate behaviour for both subjects and controls. For subjects only at 12 months ($r=.6784$, $P<.01$) was appropriate resident behaviour significantly correlated with staff:resident ratios.

For the control group 12 months and 18 months ($r=-.5897$, $P<.01$) a negative correlation between inappropriate behaviour and staff:resident ratio ($r= - 0.6365$, $P<.01$) was apparent.

Residents engaged in less inappropriate behaviour when more staff were present.

Table 97

Staff:Resident Ratio and Resident Engagement in Appropriate and Inappropriate Behaviour
Correlation Coefficients (Spearman) and Significance Levels (in parentheses)
Subjects and Controls T1-T5

	SUBJECTS		CONTROLS	
ASSESSMENT	SUBJECTS APPROPRIATE BEHAVIOUR	SUBJECTS INAPPROPRIATE BEHAVIOUR	SUBJECTS APPROPRIATE BEHAVIOUR	SUBJECTS INAPPROPRIATE BEHAVIOUR
Baseline	.4664 (.044)	-.2547 (.293)	.1941 (.471)	-.4218 (.104)
6 months	.2261 (.312)	.0561 (.804)	.4349 (.071)	-.2518 (.313)
12 months	.6784 (.002)**	-.4708 (.049)	.3961 (.116)	-.6365 (.006)**
18 months	.3973 (.226)	-.3372 (.311)	.5021 (.034)	-.5897 (.010)**
24 months	.5210 (.150)	-.7046 (.034)*	.3832 (.349)	-.3810 (.352)

* - .05
** - .01

RESIDENT ENGAGEMENT AND ADAPATIVE BEHAVIOUR

A consistent significant correlation was found between engagement in appropriate behaviour and adaptive behaviour functioning for subjects ($r = .7018$; $P<.001$) and for controls ($r = .6778$; $P<.001$). The more able a person was the more time was spent engaged in appropriate behaviour in both hospital and community settings.

SUMMARY OF FINDINGS

A very considerable amount of data were collected and generated in the evaluation of resident engagement and patterns of staff:resident interactions in both hospital and community settings.

The analysis concentrated on a number of key areas and the main results are summarised briefly below. These along with some methodological issues are examined further in the discussion.

For people who left hospital:

- there was an increase in appropriate engagement in community settings in unstructured settings only;
- there was little change in the time spent in inappropriate behaviour;
- there was a decrease in the time spent in neutral behaviour in unstructured settings only;
- staff spent more time interacting with people in community settings but only in unstructured settings;
- both closed and open staff interaction increased in the community and
- there was very little peer interaction between residents.

For people who remained in hospital:

- there was no change in the time spent engaging in appropriate behaviour;
- there was no change in time spent in neutral behaviour;
- there was little change in time spent in inappropriate behaviour;
- there was no change in the percentage of time staff spent interacting with residents;
- there was very little staff open interaction over time; and
- there was no change in the amount of peer interaction which remained very low.

Comparison of movers (subjects) with stayers (controls) showed that:

- there were some initial differences between the groups at baseline and 6 months in relation to appropriate behaviour (structured condition only) and neutral behaviour (structured condition only) which were not maintained over time;
- movers showed a tendency for an increase in time spent engaging in appropriate behaviour relative to the stayers in unstructured settings but this was only at 6 and 12 months;
- no differences were found between the groups for inappropriate behaviour and minimal differences for neutral behaviour;
- movers received significantly more staff attention (open) in unstructured settings from 6 months inwards with little differences found between the groups in other settings and for closed interaction; and
- no differences were found between the groups in relation to peer interaction.

Other findings showed that:

- appropriate resident behaviour was, in the main, not reacted to by staff, particularly in community settings. However, when staff interacted with residents, appropriate behaviour was likely to follow, at least some of the time, in both hospital and community settings;

- inappropriate resident behaviour, in both hospital and community settings was very likely to be reacted to by staff attention whereas staff attention to residents was rarely followed by resident inappropriate behaviour;

- neutral resident behaviour was more likely to be reacted to by staff in the community in unstructured settings and by staff in hospital during mealtimes. Staff attention was associated with resident neutral behaviour;

- a negative correlation was found between resident adaptive behaviour and staff interaction for people living in the community;

- no relationship was found between maladaptive behaviour and staff interaction in either setting;

- having more staff available resulted in lower rates of staff interaction but also lower rates of resident inappropriate behaviour; and

- there was no clear relationship between resident behaviour and staff attention.

Discussion

Methodological Issues

The present study involved 41 individuals with learning disabilities who were followed up for up to two years of their lives. The data presented provide a description of resident and staff behaviours within hospital and community settings over a five year period. The degree and direction of change found on the outcome measures differed both within and across settings. Some experimental hypotheses were supported, some were rejected. The data show the complex nature of the social ecologies of residential facilities for people with learning disabilities.

In considering the results, their significance to the quality of life of people with learning disabilities and how they compare with other studies, a few methodological issues are relevant to comment on.

1) The way in which behaviour is categorised has an important effect on the general view of the service when that service is described in terms of the relative frequencies or duration of particular behavioural categories. The choice of behavioural definitions for the study were related to the cultural context of behaviour. Services can encourage behaviour that would clearly be deemed inappropriate for a culturally valued person of the same age. In defining the behaviour categories it was taken that residents should behave in ways that would be deemed appropriate for culturally valued people and that services be judged in terms of the extent to which they facilitate this. Good services will tend to provide positive social consequences for appropriate behaviours and negative or no social consequence for inappropriate behaviour. The general broad categories of resident and staff behaviours employed in the present study allow for comparisons to be made with other research findings although some caution must be exercised in comparing results employing different

recording methods. Also the use of broad categories, as in the present study, may miss the more subtle variations in types of behaviour.

2) The sampling procedure adopted makes certain assumptions about the representativeness and generalisability of the observed behaviours. While sampling procedures vary from one study to another the rationale for the present study was considered appropriate for the research questions and variables under investigation. It is possible that data collected in a different way could yield different results. However, there are reasonable similarities with other study methodologies to allow some comparisons to be made.

3) The data were collected using a Psion Organiser which proved discrete and easy to use in real life settings as well as being an accurate and reliable method of recording behaviour. At the outset of the present investigation there was no appropriate programme available and specific programmes were developed in-house. Nevertheless, the programme did not allow for several behaviours to be recorded simultaneously so the extent of the analysis was somewhat limited. However, the large amount of data collected provided sufficient information to allow certain conclusions to be made with some confidence.

An analysis of a casual relationship between staff and resident behaviours was attempted although a more sophisticated sequential analysis was outwith the scope of the study.

4) Information relating to staff : resident ratios, while collected in absolute numbers, was recorded and analysed as a ratio. It is possible that situations with equal ratios (e.g. 2 staff : 10 clients; 1 staff : 5 clients) may not be associated with the same behavioural pattern from staff and residents.

5) Reliability assessments of interobserver agreements were acceptable although somewhat variable. Efforts were made to ensure that 'new observers' were trained. However, as all the observation sessions were '*in-vivo*' some undetected drift may have occurred.

6) Finally, the study design had to accommodate natural occurrences such as unequal numbers of subjects and controls at the outset; a very small percentage of 'lost' data due to observations not taking place in certain circumstances and the attrition of both subjects and controls over the life of the study.

Within the context of these methodological issues the results from the observations of resident and staff behaviours and relationship between the two are discussed below.

Resident Behaviour

Overall, resident behaviour changed little over time within or between hospital and community settings. The expected increase in levels of engaged behaviour were not realised for people who left hospital to live in the community. A tendency towards increased levels of engagement was found for subjects in unstructured settings, following the move to the community, but not for the 'controls' who remained in hospital. The initial gains for subjects relative to the controls were not maintained beyond 12 months. Levels of inappropriate behaviour remained the same and did not change for either group. Time spent engaging in neutral behaviour did point to some change in that subjects showed a small decline in this behaviour over time. However, in comparison to the control group subjects engaged in higher levels of neutral behaviour at baseline and 6 months and the decrease over time was consistent with the performance of the control group. No differences between the groups were found from 12 months onwards.

These findings, at first glance, are at odds with a number of other studies. In their review of research carried out in the U.K. Emerson and Hatton (1994) found that increased resident engagement in activity generally followed moves to less restrictive settings (e.g. Mansell and Beasley, 1993; Rawlings, 1985). However a few studies comparing hospital and community residences reported no significant changes (Bratt and Johnson, 1988; Felce, 1985; Felce et al, 1986; Felce et al, 1995).

An examination across the different setting conditions points to quite considerable variations within hospital and community settings. The results relating to levels of engaged behaviour in unstructured settings (i.e. ward, residential unit) are comparable with those found in studies of direct observation of residents' behaviour in residential settings (e.g. Cullen et al, 1983; Mansell, 1995; Thomas et al 1986). Appropriate engagement increases for people who leave hospital to live in the community relative to those who remain in hospital. However, residents in the community still spend only about one third of their time in unstructured settings engaged in appropriate behaviour, but even less in hospital settings (on average about 15% of the time). Most of the time residents engage in neutral behaviour in both hospital and community settings with inappropriate behaviour occurring for a small percentage of the time.

There is evidence from other studies, which find support from the present study, that while some gains in client engagement are maintained, there is some fall off over time (e.g. Saxby et al 1988)

In structured settings, such as a training centre or work therapy unit, subjects and controls were found to be engaged in appropriate behaviour on average for about 70% of the time. Mealtimes also saw higher levels of engaged behaviour for both groups. Few studies have looked at these settings specifically although Pettipher and Mansell (1993) found levels of engaged behaviour ranged, on

average, between 22% and 66% for people attending a day centre, dependent on client ability.

It would seem that the type of setting condition has some bearing on how residents spend their time. In settings which were 'activity' focused higher levels of engaged behaviours were observed for both people in hospital and community settings.

The variations in resident behaviour across and between settings in the present study was considerable with, at one end, some people spending as little as 2% of their time in hospital and 6% in the community engaged in appropriate behaviour while others spending near 100% of their time engaged.

There are a number of possible reasons for this.

There is some evidence that there is a relationship between level of ability and engagement. The present study found a significant relationship between resident ability as measured by adaptive behaviour and the level of engagement in appropriate behaviour. This finding is consistent with that of other studies (e.g. Crisp and Sturmey, 1984; Felce and Perry 1995a; Pettipher and Mansell, 1993). Residents with higher abilities engaged in higher levels of appropriate behaviour. It has been pointed out that clients who do not possess certain 'entry behaviours' (i.e. the ability to sit quiet, fine motor skills, attention span) are considerably disadvantaged (Crisp and Sturmey, 1984).

Although engagement may be easier for people with more abilities it is not solely dependent on ability level. In the present study higher levels of engaged behaviour were found in different setting conditions for the same group of people.

Felce and Perry (1994) reported up to 82% of the variation in engagement data across individuals may be accounted for by two factors, competence of service

users and amount of assistance received by staff. Emerson et al (1993) indicated that 52% of the variation within individuals over time in their level of engagement may be accounted for by the rate of assistance received by staff. Higher engagement levels are reported where staff are organised to provide skilled assistance and encouragement (e.g. Emerson et al, 1993; Felce et al 1995; Felce, de Kock and Repp, 1986; Mansell and Beasley, 1990;). Another factor which appears to promote user engagement is users being in very small groups (Felce and Repp, 1992) which occurs more frequently in group homes than in hospitals. This factor may contribute to the higher levels of engagement in appropriate behaviour found for people who left hospital, in unstructured settings where residents would likely be in groups of between 2 and 4. The way staff organise activities in such settings may well influence resident engagement.

The differential results found across structured and unstructured setting conditions in the present study can be explained, at least in part, by organisation of the settings and the roles staff play. The principle cause of low engagement is that people are not given things to do.

Staff Attention

The findings of increased levels of staff contact for people in the community compared to hospital are in keeping with other studies (e.g. Emerson and Hatton, 1994; Felce and Perry, 1995; Felce, Lowe and Blackman, 1995; Mansell, 1995; Thomas et al, 1986). Staff contact with residents in hospital happened infrequently, about 3% of the time increasing to an average of about 10% when people moved to the community. Over a 16 hour day residents in hospitals, on average, received 20 minutes of contact from staff whereas over a similar period of time people in staffed homes received, on average, 66 minutes of contact.

The lowest rates of staff contact in the hospital were found in unstructured settings, structured settings accounting for most of the contact. In community

settings staff contact increased but the only significant increase was found in unstructured settings.

Overall total contact received by individuals in hospital ranged from 1 - 13% and in the community residences from 1 - 33%. In examining the quality of interactions a significant increase in open interaction was observed in unstructured settings for people living in the community but this still accounted for, on average, only 4% of the total staff contact with residents. For the majority of time staff attention to residents was categorised as closed interaction that is, not allowing for a response or dialogue. So while total staff interaction with residents increased in community settings more than 50% of the interactions were of a closed type, that is not allowing for dialogue or response.

Subjects received significantly more staff 'open' interaction relative to the controls once they moved to community settings but in unstructured settings only. No differences were found between the groups in relation to staff 'closed' interaction.

The definition of staff interaction in this way was considered useful with respect to identifying those interactions that facilitate communication and social development. However, other studies (e.g. Felce and Perry, 1995; Hughes and Mansell, 1990; Mansell, 1995) have defined staff interaction further by specifying a number of sub categories measuring different aspects of the interaction. In particular of interest to the present study are those interactions defined as 'assisting' which, while not directly comparable to the definition of open interaction used here, can be compared in a more general way.

Felce and Perry (1995) found that while the levels of staff attention to residents in community housing was considerably higher than was typical in the institutions, little of it comprised direct assistance to participate in activities and the majority of staff contact was classified as neutral.

As with resident behaviour a number of factors contribute to the variable staff contact within and between hospital and community settings.

Characteristics of service users (such as personal appearance and challenging behaviour) have been found to influence the quality and quantity of staff contact (e.g. Carr, Taylor and Robinson, 1991; Dailey et al, 1974; Emerson et al, 1992; Grant and Moores, 1977), although there is little evidence that positive changes in resident behaviour act to increase or maintain staff contact (Woods and Cullen, 1983). However Duker et al (1989) found that certain resident behaviours such as looking behaviour increased interaction from staff in a hospital setting. While studies have generally found that staff contact in hospitals is relatively independent of service user behaviour (e.g. Beail, 1985; Felce et al , 1987) staff behaviour in community based services has been found to be more contingent on service user behaviour. Mansell (1995) found a slight but not significant correlation with total adaptive behaviour and staff contact while Pettipher and Mansell (1993) found clients with higher abilities received significantly less contact from staff than those who were less able in a day centre setting.

The present study found an overall significant negative relationship between adaptive behaviour and staff contact for subjects only after discharge to the community. No relationship was found between maladaptive behaviour and staff contact for either subjects or controls. These findings do not therefore support the view that it is more rewarding for staff to interact with residents who closely approximate normality than with residents who strongly deviate in this respect.

Although individual resident characteristics are likely to be important, variability in the amount of contact between individuals over time and across settings requires other factors to be explored.

Only a tenuous relationship exists between the availability of resources (e.g. staff : user ratio) and the extent and nature of staff user interaction (e.g. Dalgleish and Matthews, 1981; Felce et al, 1991; Felce and Repp, 1992; Seys and Duker, 1988).

Landesman (1988) has suggested that "the overwhelming belief which attributes the lack of sufficient social interaction with residents to staff shortages should be called the myth of understaffing" (P 108 - 109).

Staff : resident interactions have been found to occur more while staff work on their own with residents (Felce et al, 1991; Orlowska, McGill and Mansell, 1991;). The present study found no consistent relationship between staff attention and staff : resident ratio. In community settings there was a tendency for staff : resident ratios to be negatively correlated with staff interaction. This supports the view that staff spend more time engaged in organisational duties and less time providing stimulation to residents when there are greater rather than lower average levels of staff on duty (Duker et al, 1991). Felce et al (1991) suggest that there may be an overriding staff perception of the social ecology of the setting which is dominated by the size of the group and which may mean that staff do not distinguish programming opportunities when staff are more plentiful.

While not specifically examined by the present study it has been shown that increasing resources through staff training per se frequently fails to influence staff performance (e.g. Emerson and Hatton, 1994). Anderson (1987) in a review of this issue, concluded that staff training on its own almost inevitably does not lead to permanent changes in either staff or client behaviour.

It has been found however that specific organisational procedures designed to improve service quality, such as room management, do act to increase staff contact with service users (Crisp and Sturmey, 1988; Mansell et al, 1982). Clear direction and definition of roles for staff can improve performance (Cataldo and Risley, 1972; Mansell et al, 1982). Feedback to staff has been

found to have mixed effects (e.g. Bakazar, Hopkins and Suarez, 1986). Self Management techniques such as self recording have been used with some success in monitoring staff behaviour (Davis et al, 1987) and promoting higher rates of interaction (Baldwin and Hattersley, 1984).

Resident : Resident Interaction

The results confirmed findings from other studies that interactions between residents across and within settings are almost non-existent (Felce and Repp, 1992; Mansell, 1995; Perry and Felce, 1994). There was considerable individual variation between people in both hospital and in community settings. However over 70% of people, on average, in hospital and 60% of people in community settings received no interaction from other residents. Interactions when they did occur were very brief and even for people living in the community there was very little peer interaction during mealtimes, often considered a social occasion. Few studies have addressed this issue and little data is available.

The dearth of interactions between residents even in more homely settings is an issue of concern. Markova et al (1992) recognised the need for greater emphasis on helping people with learning disabilities to acquire appropriate social and communication skills. Many people with learning disabilities have had few opportunities for positive social relationships and as a consequence lack competence.

While the present study did not examine social contacts as such, a pre-requisite for developing and maintaining social relationships is the opportunity to interact. Wolfensberger (1983) states that "the most explicit and highest goal of normalisation must be the creation, support and defence of valued social roles for people who are at risk of social devaluation". One of the most important ways in which roles may be obtained (or retained) is through the development of friendships (Kings Fund, 1992). Research findings on the number and type of friendships and relationships of people with learning disabilities are not

heartening (e.g. de Kock et al, 1985; McConkey, McCormack and Naughton, 1983;).

It would seem from the finding of the present study that living in small groups in homely environments does not ensure that relationships with others will be established and for the vast majority of individuals no meaningful interaction with peers takes place.

Relationship Between Staff and Resident Behaviour

While the variation within and between service models is of considerable practical significance relatively few studies have explored possible determinants of staff contact with service users.

Within the limitations of the present study it was felt important to map possible relationships between staff and resident behaviours in an attempt to assess casual or functional relationships between resident behaviour and frequency of resident directed behaviour by staff.

Two main areas were under examination. Firstly, the probability of different resident behaviours being attended to by staff and, secondly, the probability of staff attention being associated with different resident behaviours.

The results demonstrated that, in the main, the probability of resident appropriate behaviour being attended to by staff was low, particularly in community settings. However, for inappropriate behaviour there was a significant relationship with staff attention across and within both settings. While it may seem that staff are indiscriminate in their attention to resident behaviour these findings point to the likelihood of inappropriate behaviour being attended to by staff rather than appropriate or neutral behaviours.

The consequence of staff attention for the encouragement or discouragement of inappropriate behaviour are unclear. The view that good services will provide social consequence for appropriate behaviours and negative or no social consequence for inappropriate or neutral behaviour was not borne out here. However the findings suggest that appropriate resident behaviour is a likely consequence of staff attention. Other studies examining similar issues show some mixed findings.

Felce, Lowe and Blackman (1995) found that challenging behaviour (which is not necessarily the same as inappropriate behaviour) received the least share of staff attention in both hospital and community settings and that more attention was, on average directed towards residents in both hospital and community settings when they were disengaged (i.e. neutral behaviour) than when engaged. The only category of resident behaviour with a moderately high probability of attracting staff attention was social engagement, a behaviour which did not occur a lot. There was generally a lack of a consistent relationship in both hospital and community settings in the manner in which staff attended to resident behaviour. Felce and Repp (1992) found that 57% of staff attention in houses and 33% in hospital was for appropriate behaviour but overall there would appear to be a general absence of discrimination by staff as to the timing and content of their interactions with residents.

Other effects have been identified, such as increasing staff interaction will result in decreases in resident inappropriate behaviour (Baldwin and Hattersley, 1984). Findings from the present study found no significant relationship between staff interaction and resident inappropriate behaviour. However a 'circular' relationship may exist. When staff interacted with residents they were more likely to attend to resident inappropriate behaviour than other behaviour. As a consequence of an interaction residents were likely to show appropriate behaviour.

Of particular interest is the effect staff attention has on resident behaviour. There is some evidence that increases in staff interaction results in decreases in resident inappropriate behaviour (Bladwin and Hatersley, 1994). Results from studies show that resident engagement in appropriate behaviour is most likely to result from staff attention. This is in keeping with studies which have shown that increased staff interaction results in higher levels of engaged behaviours, particularly when the interaction is 'assisting' in nature (e.g. Felce and Perry, 1995; Felce and Repp, 1992, Mansell, 1995). It is of interest to note that, in the present study, the increase in resident engagement found for subjects corresponds with an increase in staff attention in unstructured settings.

Summary

Despite the somewhat complex and differing findings of studies some conclusions can be drawn from the literature and outcomes of the present study:

(i) Patterns of activity can be used as indicators of an important dimension of normalisation, namely rhythm of life (Nirje, 1980). In this way the provision of adequate opportunities for engagement can be viewed as an indicator of how service providers view their clients (e.g. Pettipher and Mansell, 1993).

The degree to which a person spends his/her time engaged in social, personal, household leisure or other activities typical of daily living (as opposed to having nothing to do, being passive, or engaging in aimless challenging behaviour) is a significant facet of quality of life (Bellamy et al, 1990; Felce, 1986; Hewson, 1991) O'Brien (1987) has defined five accomplishments as essential goals for human services: - community presence, community participation, competence, choice and rights, dignity and respect - which are consistent with the theme of normalisation (Wolfensberger and Glenn, 1975). In the definition of each one, he emphasises the importance of participation in valued

activity - accomplishments gained as a result of one's participation in every day life; it is a consequence of repeated engagement in activity. It is apparent from the findings of the present study, and others, that for many people with learning disabilities meaningful engagement is not a reality for a lot of their time, even in community settings.

(ii) The extent of assistance received from staff is probably the key to participation in activity for people who lack independent abilities. Mansell et al (1987) argued that providing direct assistance to enable and facilitate client participation in every day tasks is one of the most important features of good practice in residential settings for people with learning disabilities. Despite this, staff do not appear to interact with residents in ways that encourage and reinforce appropriate behaviour and engagement in valued activities.

(iii) Limited interaction reduces opportunities to model appropriate forms of relating to others. Positive interactions should lead to, or at least be associated with, a higher quality of life for people with learning disabilities by an increase in their competencies. It is apparent that for many people with learning disabilities meaningful interaction with others is almost non-existent.

(iv) The relationship between outcome and the nature of the service as represented by the size of the setting, building design, location, staff and other factors is mediated by the internal organisation, working methods and procedures which shape what staff do. It is clear that moving people from one setting to another, increasing staff numbers per se, or providing training for staff are, on their own, not sufficient to bring about any real change to the quality of life for people with learning disabilities. Further research exploring the relationship between staff and resident behaviours should contribute to the understanding of these dynamics and how to maximise the opportunities afforded people with learning disabilities.

CHAPTER 12

CONCLUSION

The three studies reported in this thesis have provided a valuable contribution to the field of research as to how to provide services for people with learning disabilities which will lead to high quality lifestyles. It is clear that quality of life for people with learning disabilities comprises of the same factors (in the main) as quality of life for people without disabilities. It is also apparent that people with learning disabilities can be meaningfully involved in assessing their quality of life and aspirations. However there are concerns about the validity of assessing quality of life from a subjective standpoint with people with learning disabilities. This is due, in the main, to the methodological and conceptual problems inherent in this area(Hatton1998). More debate about quality of life as a concept and of practice is required.

The outcomes from the studies support the general view that large institutions are difficult environments in which to arrange good services and there are no good reasons for people remaining there. People who are discharged from hospital to community settings are not worse off although initial gains in some aspects of functioning tend to level off after a few months rather than continue to improve. The community settings studied have shown further evidence that the adoption of an ordinary housing model of service has resulted in quality of life improvements when data on quality of lifestyles and living units, personal satisfaction and staff resident interactions are compared to those typically found in the institutional service. However, the level of what is being achieved, although better, may still be considered to leave much to desire. For example, residents were not occupied in constructive behaviour for at least two thirds of their day and showed little evidence of developing skills and repertoires to enable them to have a valued role within their community and meaningful presence. While people were physically integrated by the very nature of living in the community, there is no evidence that social integration, development of relationships and social networks (cf Storey, 1993) were a reality. The returns form the greater opportunities on staff availability in the community remain to be realised. These data support assertions by many professionals in the field that physical integration does not generally translate to social integration (cf Lynch, Kellow and Willson1998) Pedlar (1986) has pointed

out that in both Sweden and the United States "social integration appears to be far more elusive than physical and functional integration" (p.281).

This presents a challenge to the normalisation philosophy and its impact on the social integration of people with learning disabilities.

The findings from the present investigation supports other research which has emphasised that the pursuit of quality in ordinary houses entails more than just the provision of ordinary environments. The social address model of service provision which considers where a person lives to be of particular importance, is not adequate on its own. While moving from a large institution to a smaller community residence may be a necessary condition for an improved quality of life, it is rarely a sufficient one.

Although many definitions of quality of life have been proposed, most focus on social integration as a critical component (Hughes,1995). If distal effects of community placement (increased socialisation and community integration) are to be realised we must provide support and programming in the area for consumers.

The subjects in this study were moving into community-based services with a commitment to the normalisation ideal but no systematic programme of sophistication or comprehensive therapeutic services. This is probably a common scenario in most services. It is not surprising, therefore, that significant improvements in the areas of skills, competencies and levels of engagement were not found. However, a tendency towards improvements were found in a number of areas giving some cause for believing that clients could acquire new and socially valued repertoires. To capitalise on this, it would be necessary, though, to take seriously all the ramifications of a commitment to the normalisation philosophies (cf Knoll & Ford, 1987). Included in this should be the hope for clients that valued behaviours will be taught.

However, Cullen (1991) cautions that there must be continuing discussion of the distinction between valuing roles and valuing people. It may be that, for some people, it should be accepted that it may not be feasible to establish many new repertoires. However service providers, in consultation with people with learning disabilities and/or their advocates should take seriously the importance of establishing skills and repertoires as a specific aim of the service rather than hoping that such changes will happen as a result of relocation.

In addressing the claims that the goals of the service are not to increase behavioural competence, they are to provide 'normal' living in 'ordinary' environments (cf Dever, 1990), the challenge, surely, is one that meets the aspirations of the five service accomplishments as identified by O'Brien, (1987). To date, results from studies (this included) appear to demonstrate that services have fallen short of these aims and that there is still some way to go before we can say with confidence that community based services are meeting all the needs of people with learning disabilities.

In the early 1900's the original aim of 'institutionalisation' was to provide training and education along with opportunities for constructive activities for people with learning disabilities. The reality fell short of the original ideals.

Now approaching the 21st century 'deinstitutionalisation' is also in danger of not realising its ideals and aims for people with learning disabilities.

Then it was accepted, now there is no excuse.

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LIST OF APPENDICES

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Appendix 1

Social Vailidty Questionnaire -Community Sample

UNIVERSITY OF ST. ANDREWS

We would like you to take part in a study which is examining some aspects of services for people with a mental handicap. You can help by answering a few questions - it should take less than 15 minutes of your time.

The first two sections are concerned with the importance to you of a number of aspects of everyday life.

The final section asks about your opinion of some aspects of services for mentally handicapped people.

Would you also be kind enough to complete the following questions:

1. Sex M or F (circle one)

2. Age Under 20 (circle one)
   21 - 30
   31 - 40
   41 - 50
   above 50

3. How much contact would you say you have with mentally handicapped people?

   Virtually none (circle one)

   A little

   Quite a lot

Part One

Please circle which number best describes each item in terms of its importance to you.

Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
1	2	3	4	5

Access to Facilities

1.	How important is it that local shops are within easy access?	1	2	3	4	5
2.	How important is it that public transport is within easy access?	1	2	3	4	5
3.	How important is it that recreational/social facilities are within easy access?	1	2	3	4	5

How important is it that you should not have to use the following in a large group:

4.	Local shops?	1	2	3	4	5
5.	Public Transport	1	2	3	4	5
6.	Recreational/Social Facilities?	1	2	3	4	5
7.	How important is it to live permanently with less than five others?	1	2	3	4	5
8.	How important is it for people to address each other informally, e.g. by Christian name?	1	2	3	4	5
9.	How important is it to go on holiday with small rather than large groups?	1	2	3	4	5
10.	How important is it that rooms are cleaned regularly?	1	2	3	4	5

How important are the following:

11.	For toilets to have doors?	1	2	3	4	5
12.	For toilets to lock?	1	2	3	4	5
13.	For toilets to have toilet paper?	1	2	3	4	5

14.	To be able to use the toilet at any time?	1	2	3	4	5
15.	To have free access to hand basins?	1	2	3	4	5
16.	To bathe alone?	1	2	3	4	5
17.	To have access to a mirror?	1	2	3	4	5
18.	To have the choice of a single room?	1	2	3	4	5
19.	For all rooms to have curtains/blinds?	1	2	3	4	5
20.	To have a say in which TV programme is shown?	1	2	3	4	5
21.	To have a comfortable chair per person in your home?	1	2	3	4	5
22.	To have a wastepaper basket in each room?	1	2	3	4	5
23.	To choose when to put your light out at night?	1	2	3	4	5
24.	To be involved in any plans concerning yourself?	1	2	3	4	5
25.	To have access to those plans?	1	2	3	4	5
26.	To regularly see an account of your finances?	1	2	3	4	5
27.	To have easy access to advice regarding finances?	1	2	3	4	5
28.	To have your last main meal after 5.30 p.m.?	1	2	3	4	5
29.	To choose your own meal?	1	2	3	4	5
30.	For visitors to be offered refreshments?	1	2	3	4	5
31.	To be able to receive phone calls?	1	2	3	4	5
32.	To have access to a phone?	1	2	3	4	5
33.	To have a phone for your use only?	1	2	3	4	5
34.	For visitors to be able to call at any time?	1	2	3	4	5
35.	To have overnight facilities for family/friends?	1	2	3	4	5
36.	To be consulted about your own home decor?	1	2	3	4	5

37.	For the decor to be varied from room to room?	1	2	3	4	5
38.	For the decor to be age appropriate?	1	2	3	4	5
39.	To have regular training in fire practice?	1	2	3	4	5
40.	To have your own front door key?	1	2	3	4	5
41.	To have free access to your kitchen?	1	2	3	4	5
42.	To have free access to your bathroom?	1	2	3	4	5
43.	To have free access to your bedroom?	1	2	3	4	5
44.	How important is it to be allowed out alone?	1	2	3	4	5
How important is it to have ready access to:-						
46.	Public Transport?	1	2	3	4	5
47.	Discos/Parties?	1	2	3	4	5
48.	Shows?	1	2	3	4	5
49.	Outings?	1	2	3	4	5
50.	Holidays?	1	2	3	4	5
51.	Social Clubs?	1	2	3	4	5
52.	Shops?	1	2	3	4	5
53.	How important is it that birthdays are celebrated?	1	2	3	4	5
How important is it for adults to have their own:-						
54.	Toys?	1	2	3	4	5
55.	Games?	1	2	3	4	5
56.	Books?	1	2	3	4	5
57.	Jewellery/Watch?	1	2	3	4	5
58.	Radio/Cassette/Hi-Fi?	1	2	3	4	5
59.	How important is it not to have restrictions on the use of any of these?	1	2	3	4	5
60.	How important is it to be able to buy your own clothes?	1	2	3	4	5

61.	How important is it to be able to choose which clothes to wear?	1	2	3	4	5

How important is it to have your own and sufficient:-

62.	Underwear	1	2	3	4	5
63.	Top Clothing?	1	2	3	4	5
64.	Outdoor Clothing?	1	2	3	4	5
65.	Footwear?	1	2	3	4	5
66.	Night Clothing?	1	2	3	4	5
67.	How important is it to have a place to store personal items?	1	2	3	4	5
68.	How important is it to be able to help prepare meals?	1	2	3	4	5
69.	How important is it to be able to have drinks/snacks between meals?	1	2	3	4	5
70.	How important is it to regularly visit family/friends?	1	2	3	4	5
71.	How important is it to have regular visits from family/friends?	1	2	3	4	5
72.	How important is it to go on holiday with family/friends during the year?	1	2	3	4	5
73.	How important is it that prescribed drugs are regularly reviewed by a doctor?	1	2	3	4	5
74.	How important is it to be able to stay up later than 9 p.m.	1	2	3	4	5

Part II

Please circle which number best describes each item in terms of its importance to you.

Not Important	Slightly Important	Moderately Important	Very Important	Extremely Important
1	2	3	4	5

1.	How important is it to have regular staff meetings in a setting where mentally handicapped people live?	1	2	3	4	5
2.	How important is it to have regular staff and management meetings in a setting where mentally handicapped people live?	1	2	3	4	5
3.	How important is it to have regular staff and client meetings in a setting where mentally handicapped people live.	1	2	3	4	5
4.	How important is it to have regular client meetings in a setting where mentally handicapped people live?	1	2	3	4	5

How important is it, if required for a mentally handicapped person to have access to the following:

5.	Speech Therapist?	1	2	3	4	5
6.	Physiotherapist	1	2	3	4	5
7.	Social Worker?	1	2	3	4	5
8.	Psychiatrist?	1	2	3	4	5
9.	Psychologist?	1	2	3	4	5
10.	G.P.s?	1	2	3	4	5
11.	Community Nurse?	1	2	3	4	5
12.	For staff working with these clients to have contact with the above services?	1	2	3	4	5
13.	How important is it to have a structured day placement e.g. an adult training centre?	1	2	3	4	5

14.	How important is it for residential staff to have contact with the clients' day placement staff?	1	2	3	4	5
15.	How important is it for a mentally handicapped person to have a written individual programme plan?	1	2	3	4	5
16.	How important is it that a mentally handicapped person's family be regularly informed about his/her progress?	1	2	3	4	5
17.	How important is it that a mentally handicapped person addresses staff informally, e.g. by Christian name?	1	2	3	4	5
18.	How important is it to have free access to the staffroom?	1	2	3	4	5
19.	How important is it for staff to eat with mentally handicapped persons?	1	2	3	4	5
20.	How important is it for staff to address mentally handicapped people informally?	1	2	3	4	5
21.	How important is it that staff have daily one to one contact with a client?	1	2	3	4	5
22.	How important is it that this contact should be over one hour per day?	1	2	3	4	5

Appendix 2

Social Validity Study: Percentage Agreement
Community Group

Appendix. 2

Social Validity Study: percentage agreement - Community Group

Question No.	Absolute	Within 1 scaled point
1	82	100
2	64	100
3	86	100
4	50	86
5	59	86
6	59	86
7	54	82
8	68	100
9	59	82
10	32	95
11	64	100
12	59	91
13	73	100
14	64	100
15	54	100
16	59	91
17	41	95
18	54	91
19	23	82
20	54	95
21	54	86
22	54	100
23	54	91
24	86	100
25	86	95
26	59	95
27	45	86
28	59	91
29	45	95
30	59	95
31	59	95
32	64	95
33	45	82
34	50	86
35	54	100
36	50	95
37	64	86
38	45	91
39	59	86
40	68	95
41	54	95
42	64	100
43	73	100
44	64	100
45	59	95
46	59	91
47	64	82
48	68	91
49	68	86
50	54	91
51	64	86
52	64	91
53	50	77
54	54	86
55	41	95
56	73	91
57	59	82
58	45	95
59	45	91
60	41	100
61	50	100
62	68	100
63	64	100
64	73	100
65	68	100
66	45	91

Appendix 2 (Continued)

Question No.	Absolute	Within 1 scaled point
67	73	95
68	41	91
69	73	86
70	68	95
71	82	95
72	59	95
73	64	91
74	73	95

Part II

Question No.	Absolute	Within 1 scaled point
1	68	95
2	73	95
3	59	95
4	59	100
5	77	100
6	73	100
7	77	100
8	73	95
9	82	100
10	77	95
11	73	100
12	68	95
13	68	100
14	64	95
15	50	91
16	73	95
17	59	100
18	54	100
19	50	100
20	41	95
21	59	100
22	64	100

Appendix 3

Social Validity Study: Ratings of Importance

Appendix 3

Social Validity Study: Ratings of Importance - Community Group
Level of Importance

Question Number	Not Important 1		2		3		4		Extremely Important 5		Median Value of Importance
	No.	%	No.	%	No.	%	No.	%	No.	%	
1	4	2	17	8.5	82	41	60	30	37	18.5	3
2	2	10	19	9.5	47	23.5	63	31.5	51	25.5	4
3	12	6	23	11.5	68	34	66	33	31	15.5	3
4	42	21	25	12.5	56	28	34	17	43	21.5	3
5	46	23	27	13.5	53	26.5	33	16.5	41	20.5	3
6	29	19.5	20	10	63	31.5	41	20.5	37	18.5	3
7	32	16	8	4	30	15	43	21.5	87	43.5	4
8	12	6	9	4.5	50	25	63	31.5	66	33	4
9	22	11	14	7	51	25.5	51	25.5	62	31	3
10	6	3	9	4.5	33	16.5	73	36.5	79	39.5	4
11	2	1	2	1	10	10	34	17	152	76	3
12	8	4	4	2	27	13.5	48	24	113	56.5	5
13	0	0	1	0.5	0	0	29	14.5	170	85	5
14	0	0	3	1.5	5	2.5	29	14.5	163	81.5	5
15	2	1	3	1.5	22	11	55	27.5	118	59	5
16	5	2.5	4	2	18	9	34	17	139	69.5	5
17	13	6.5	18	9	64	32	56	28	49	24.5	4
18	11	5.5	9	4.5	31	15.5	52	26	97	48.5	4
19	12	6	14	7	34	17	52	26	89	44.5	4
20	15	7.5	16	8	79	39.5	54	27	36	18	3
21	15	7.5	7	3.5	45	22.5	71	35.5	72	31	4
22	36	18	59	29.5	54	27	33	16.5	18	9	3
23	6	3	7	3.5	38	19	60	30	89	44.5	4
24	0	0	0	0	8	4	32	16	160	80	5
25	0	0	1	0.5	10	5	33	16.5	156	78	5
26	2	1	2	1	17	8.5	49	24.5	130	65	5
27	6	3	6	3	34	17	71	35.5	83	41.5	4
28	36	18	22	11	56	28	39	18.5	47	23.5	3
29	8	4	17	8.5	36	18	73	36.5	66	33	4
30	4	2	4	2	49	24.5	87	43.5	56	28	4
31	1	0.5	2	1	25	12.5	62	31	110	55	5
32	2	1	5	2.5	30	15	56	28	107	53.5	5
33	11	5.5	28	14	44	22	52	26	65	32.5	4
34	3	1.5	13	6.5	40	20	70	35	74	37	4
35	5	2.5	20	10	58	29	57	28.5	60	30	4
36	5	2.5	12	6	45	22.5	58	29	80	40	4
37	12	6	21	10.5	50	25	52	26	65	32.5	4
38	14	7	11	5.5	59	29.5	64	32	52	26	4
39	28	14	29	14.5	51	25.5	44	22	48	24	3
40	3	1.5	3	1.5	12	6	46	23	136	68	5
41	1	0.5	2	1	13	6.5	52	26	132	66	5
42	0	0	1	0.5	6	3	47	23.5	146	73	5
43	0	0	1	0.5	5	2.5	33	16.5	161	80.5	5
44	1	0.5	3	1.5	16	8	45	22.5	135	67.5	5
45	6	3	0	0	16	8	45	22.5	133	66.5	5
46	12	6	11	5.5	34	17	66	33	77	39.5	4
47	17	8.5	26	13	61	30.5	52	26	44	22	3
48	13	6.5	21	10.5	62	31	59	29.5	45	22.5	4
49	10	5	9	4.5	40	20	71	35.5	60	30	4
50	3	1.5	9	4.5	29	14.5	74	37	85	42.5	4
51	27	13.5	25	12.5	46	23	57	28.5	45	22.5	4
52	6	3	6	3	22	11	74	37	92	46	4
53	18	9	19	9.5	51	25.5	59	29.5	53	26.5	4
54	70	35	42	21	44	22	30	15	14	7	2
55	25	12.5	46	23	66	33	46	23	17	8.5	3
56	12	6	11	5.5	49	24.5	73	36.6	55	27.5	4
57	13	6.5	11	5.5	51	25.5	71	35.5	54	27	4
58	6	3	11	5.5	52	26	69	34.5	62	31	4

Appendix 3 (Cont.)

Question Number	Not Important 1		2		3		4		Extremely Important 5		Median Value of Importance
	No.	%	No.	%	No.	%	No.	%	No.	%	
59	6	3	9	4.5	34	17	62	31	89	44.5	4
60	6	3	3	1.5	18	9	71	35.5	102	51	5
61	1	0.5	2	1	14	7	63	31.5	120	60	5
62	1	0.5	0	0	7	35	37	18.5	155	77.5	5
63	0	0	1	0.5	10	5	54	27	135	67.5	5
64	0	0	2	1	12	6	55	27.5	131	65.5	5
65	0	0	0	0	10	5	43	21.5	147	73.5	5
66	15	7.5	12	6	15	7.5	39	19.5	119	59.5	5
67	2	1	6	3	15	7.5	70	35	107	53.5	5
68	18	9	19	9.5	56	28	65	32.5	42	21	4
69	10	5	16	8	61	30.5	55	27.5	58	29	4
70	1	0.5	6	3	34	17	64	32	95	47.5	4
71	1	0.5	7	3.5	33	16.5	67	33.5	92	46	4
72	13	6.5	20	10	40	20	73	36.5	54	27	4
73	8	4	6	3	10	5	42	21	134	67	5
74	3	1.5	8	4	21	10.5	44	22	124	62	5

Part II

Question Number	Important 1		2		3		4		Not Important 5		Median Value of Importance
	No.	%	No.	%	No.	%	No.	%	No.	%	
1	2	1	1	0.5	10	5	62	31	125	62.5	5
2	2	1	1	0.5	12	6	62	31	123	61.5	5
3	0	0	1	0.5	10	5	63	31.5	126	63	5
4	0	0	2	1	16	8	64	32	118	59	5
5	0	0	0	0	7	3.5	44	22	149	74.5	5
6	1	0.5	1	0.5	4	2	47	23.5	147	73.5	5
7	6	3	2	1	18	9	41	20.5	133	66.5	5
8	4	2	2	1	11	5.5	44	22	139	69.5	5
9	1	0.5	1	0.5	10	5	43	21.5	145	72.5	5
10	2	1	2	1	6	3	34	17	156	78	5
11	2	1	3	1.5	12	6	43	21.5	140	70	5
12	1	0.5	6	3	12	6	60	30	121	60.5	5
13	0	0	2	1	21	10.5	71	35.5	106	53	5
14	1	0.5	3	1.5	22	11	66	33	108	54	5
15	0	0	5	2.5	42	21	72	36	81	40.5	4
16	2	1	6	3	9	4.5	62	31	121	60.5	5
17	5	2.5	11	5.5	37	18.5	82	41	65	32.5	4
18	23	11.5	26	13	81	40.5	40	20	30	15	3
19	4	2	21	10.5	58	29	60	30	57	28.5	4
20	4	2	6	3	37	18.5	71	35.5	82	41	4
21	2	1	6	3	21	10.5	66	33	105	52.5	5
22	7	3.5	16	8	54	27	57	28.5	66	33	4

Appendix 4

Social Validity Study: Learning Disability Group Questionnaire

SOCIAL VALIDITY STUDY - LEARNING DISABILITY GROUP QUESTIONNAIRE

Coding Sheet

Name/Number: **Sex:**

Age: **Residence:**

PART ONE

Tick whether the subject's response is categorised as important (Yes) or unimportant (No)

1.	Having shops near your house	Y	N
2.	Having buses near your house	Y	N
3.	Having places to meet people/do things you enjoy near your house	Y	N
4.	To go to the shops with just a few people	Y	N
5.	To go on buses with just a few people	Y	N
6.	To live with less than five people	Y	N
7.	To call people by their first name	Y	N
8.	To go on holiday with just a few people	Y	N
9.	To clean rooms every week	Y	N
10.	To have a toilet door	Y	N
11.	To have a lock on the toilet door	Y	N
12.	To have toilet paper in the toilet	Y	N
13.	To go to the toilet when you want to	Y	N
14.	To wash when you want	Y	N
15.	To have a bath alone	Y	N
16.	To have a mirror	Y	N
17.	To have a single room of your own	Y	N
18.	To have curtains/blinds on your windows	Y	N
19.	To choose what to watch on TV	Y	N
20.	To have a comfortable chair to sit on	Y	N
21.	To have a rubbish bin in each room	Y	N
22.	To go to bed when you want	Y	N
23.	To have a say in your future plans	Y	N
24.	To see any written plans about you	Y	N
25.	To know how much money you have	Y	N
26.	To have someone to help you with your money	Y	N
27.	To have your dinner after 5.30 at night	Y	N
28.	To choose what you want to eat	Y	N
29.	To have something to give friends to eat/drink	Y	N
30.	For friends to visit at any time they like	Y	N
31.	To have a phone to use	Y	N
32.	For friends to be able to stay overnight	Y	N
33.	To choose how your home is decorated	Y	N
34.	For each room to be decorated differently	Y	N
35.	Not to have childish things in your room	Y	N
36.	To have fire drills	Y	N
37.	To have your own front door key	Y	N
38.	To use the kitchen when you want	Y	N
39.	To use the bedroom when you want	Y	N
40.	To be able to go out by yourself	Y	N
41.	To be able to cross roads by yourself	Y	N
42.	To be able to easily use buses/trains	Y	N
43.	To be able to easily go to discos/parties	Y	N

44.	To be able to easily go on outings/holidays	Y	N
45.	To be able to easily go to the shops	Y	N
46.	To have cards and presents on your birthday	Y	N
47.	To have toys	Y	N
48.	To have games	Y	N
49.	To have books	Y	N
50.	To have jewellery/a watch	Y	N
51.	To have a radio/cassette/hi-fi	Y	N
52.	To be able to use these things when you want	Y	N
53.	To buy your clothes	Y	N
54.	To choose which clothes to wear	Y	N
55.	To have your own underwear	Y	N
56.	To have your own top clothing eg jumpers/trousers	Y	N
57.	To have your own outdoor clothing	Y	N
58.	To have your own shoes/slippers	Y	N
59.	To have your own night clothing	Y	N
60.	To have a safe place to keep your things	Y	N
61.	To be able to help make meals	Y	N
62.	To be able to have drinks/snacks between meals	Y	N
63.	To see family/friends often	Y	N
64.	To be able to go on holiday with family/friends	Y	N
65.	To have your medicine checked often by a doctor	Y	N
66.	To be able to stay up later than 9 at night	Y	N
67.	To have staff meetings often	Y	N
68.	To have meetings between staff and their bosses often	Y	N
69.	To have meetings between staff and M.H. people often	Y	N
70.	To have meetings between M.H. people often	Y	N
71.	To see a speech therapist when you need to	Y	N
72.	To see a physiotherapist when you need to	Y	N
73.	To see a social worker when you need to	Y	N
74.	To see a psychiatrist when you need to	Y	N
75.	To see a doctor when you need to	Y	N
76.	To see a psychologist when you need to	Y	N
77.	To see a community nurse when you need to	Y	N
78.	For carers to get reports from these people about how you are	Y	N
79.	For the different carers to talk to each other about how you are	Y	N
80.	To have things to do each day	Y	N
81.	To have a written plan about your future	Y	N
82.	For your family to know how you are keeping	Y	N
83.	To call staff by their first names	Y	N
84.	To be able to go to the staff room when you want	Y	N
85.	To be able to eat with staff	Y	N
86.	To be able to talk to staff each day	Y	N
87.	To be able to talk to staff for an hour or more each day	Y	N

APPENDIX 5

Social Validity Study: Learning Disability Group Percentage Agreements

SOCIAL VALIDITY STUDY - LEARNING DISABILITY GROUP
PERCENTAGE AGREEMENTS

PERCENTAGE AGREEMENT

Question No	Test-retest	Inter-rater
1	87	67
2	80	87
3	87	87
4	87	80
5	87	87
6	93	87
7	93	93
8	80	73
9	93	100
10	93	93
11	93	93
12	100	100
13	93	93
14	93	93
15	100	100
16	93	80
17	93	100
18	93	93
19	93	100
20	73	93
21	73	87
22	93	93
23	93	87
24	93	87
25	93	73
26	87	100
27	80	80
28	93	93
29	100	100
30	100	100
31	100	100
32	93	87
33	73	87
34	80	73
35	73	80
36	100	100
37	93	93
38	100	100
39	100	100
40	87	73
41	87	87
42	80	93
43	93	100
44	93	93
45	100	100
46	93	100
47	80	93
48	87	67
49	87	67
50	100	100
51	100	100
52	100	100

PERCENTAGE AGREEMENT

Question No		
53	93	100
54	100	100
55	100	100
56	100	100
57	100	100
58	100	100
59	100	100
60	100	100
61	93	100
62	87	93
63	100	100
64	93	100
65	100	100
66	93	93
PART II		
1	87	93
2	80	93
3	93	100
4	73	80
5	93	100
6	73	80
7	100	100
8	93	87
9	87	87
10	87	93
11	87	87
12	93	93
13	100	100
14	93	93
15	87	87
16	100	93
17	100	93
18	87	93
19	87	93
20	93	93
21	93	93

Appendix 6

Social Validity Study: Learning Disability Group
Number and percentage of subjects rating items as important and unimportant

Appendix 6

SOCIAL VALIDITY STUDY
LEARNING DISABILITY GROUP

Number and percentage of subjects rating items as important (Yes) and unimportant (No)

	RATING			
	YES		NO	
Question	Number	%	Number	%
1	45	80.4	11	19.6
2	45	80.4	11	19.6
3	50	89.3	6	10.7
4	52	92.9	4	7.1
5	52	92.9	4	7.1
6	52	92.9	4	7.1
7	48	85.7	8	14.3
8	44	78.6	12	21.4
9	50	89.3	6	10.7
10	53	94.6	3	5.4
11	51	91.1	5	8.9
12	56	100	0	0.0
13	56	100	0	0.0
14	55	98.2	1	1.8
15	55	98.2	1	1.8
16	51	91.1	5	8.9
17	51	91.1	5	8.9
18	55	98.2	1	1.8
19	52	92.9	4	7.1
20	51	91.1	5	8.9
21	44	78.6	12	21.4
22	50	89.3	6	10.7
23	53	94.6	3	5.4
24	53	94.6	3	5.4
25	51	91.1	5	8.9
26	51	91.1	5	8.9
27	32	57.1	24	42.9
28	50	89.3	6	10.7
29	56	100	0	0.0
30	56	100	0	0.0
31	54	96.4	2	3.6
32	50	89.3	6	10.7
33	47	83.9	9	16.1
34	49	87.5	7	12.5
35	51	91.1	5	8.9
36	54	96.4	2	3.6
37	50	89.3	6	10.7
38	54	96.4	2	3.6
39	56	100	0	0.0
40	48	85.7	8	14.3
41	51	91.1	5	8.9
42	53	94.6	3	5.4
43	53	94.6	3	5.4
44	53	94.6	3	5.4
45	56	100	0	0.0
46	52	92.9	4	7.1
47	23	41.1	33	58.9
48	36	64.3.	20	35.7
49	44	78.6	12	21.4

	RATING			
	YES		NO	
Question	Number	%	Number	%
50	55	98.2	1	1.8
51	55	98.2	1	1.8
52	56	100	0	0.0
53	47	83.9	9	16.1
54	52	92.9	4	7.1
55	56	100	0	0.0
56	56	100	0	0.0
57	56	100	0	0.0
58	56	100	0	0.0
59	56	100	0	0.0
60	56	100	0	0.0
61	54	96.4	2	3.6
62	52	92.9	4	7.1
63	56	100	0	0.0
64	55	98.2	1	1.8
65	54	96.4	2	3.6
66	55	98.2	1	1.8
PART II				
1	51	91.1	5	8.9
2	51	91.1	5	8.9
3	48	85.7	8	14.3
4	50	89.3	6	10.7
5	52	92.9	4	7.1
6	50	89.3	6	10.7
7	52	92.9	4	7.1
8	49	87.5	7	12.5
9	52	92.9	4	7.1
10	50	89.3	6	10.7
11	50	89.3	6	10.7
12	53	94.6	3	5.4
13	53	94.6	3	5.4
14	54	96.4	2	3.6
15	54	96.4	2	3.6
16	55	98.2	1	1.8
17	51	91.1	5	8.9
18	46	82.1	10	17.9
19	47	83.9	9	16.1
20	52	92.9	4	7.1
21	50	89.3	6	10.7

Appendix 7

Study 2 - Subjects' Individual Characteristics

SUBJECTS - INDIVIDUAL CHARACTERISITCS **APPENDIX 7**

No	Sex	Age	Years in Hospital	Level of Disability	ABS A TOTAL	ABS B TOTAL	Final Assessment
1	F	52	26	Mild	210	8	12 months
2	M	26	18	Severe	88	30	12 months
3	F	53	36	Moderate	194	12	12 months
4	F	50	31	Mild	220	20	12 months
5	F	25	19	Profound	49	55	12 months
6	M	33	25	Profound	97	47	12 months
7	M	41	22	Moderate	197	12	12 months
8	F	24	17	Moderate	168	24	18 months
9	F	45	16	Moderate	223	19	12 months
10	M	35	20	Moderate	186	35	12 months
11	M	57	10	Moderate	128	24	18 months
12	F	31	26	Severe	149	35	18 months
13	F	36	21	Mild	194	12	24 months
14	F	61	19	Moderate	228	1	18 months
15	F	37	21	Moderate	187	6	24 months
16	F	31	21	Moderate	207	20	24 months
17	F	66	20	Mild	207	7	24 months
18	M	74	2	Mild	221	8	24 months
19	M	38	20	Severe	121	5	24 months
20	M	36	20	Mild	191	18	24 months
21	M	43	39	Moderate	243	15	30 months
22	M	27	18	Severe	204	6	30 months
23	M	30	17	Moderate	236	1	30 months
24	M	33	29	Moderate	220	3	30 months
25	M	32	17	Mild	247	13	6 months
26	F	41	19	Severe	191	0	30 months
27	F	53	17	Moderate	191	3	30 months
28	F	21	15	Moderate	128	27	30 months
29	F	22	8	Moderate	164	21	30 months
30	F	24	18	Severe	50	45	30 months
31	F	52	19	Mild	222	21	30 months
32	M	36	21	Mild	208	8	30 months
33	M	31	15	Mild	148	38	30 months
34	M	30	29	Profound	48	94	30 months
35	M	26	22	Severe	83	52	30 months
36	M	67	29	Moderate	146	7	30 months
37	M	43	2	Moderate	183	2	30 months
38	M	35	20	Moderate	211	11	30 months
39	M	38	14	Moderate	213	5	30 months
40	M	38	35	Moderate	193	18	30 months
41	M	48	40	Moderate	188	14	30 months
42	F	47	12	Mild	213	20	30 months
43	F	20	17	Moderate	202	17	30 months
44	F	42	34	Moderate	178	47	30 months
45	F	36	30	Moderate	193	7	24 months
46	M	49	17	Moderate	242	10	30 months
47	M	40	25		197	16	30 months
48	M	59	42		157	9	30 months
49	M	35	18	Moderate	191	27	30 months
50	M	40	37		195	38	30 months

Appendix 8

Study 2 - Controls' Individual Characteristics

CONTROLS - INDIVIDUAL CHARACTERISTICS **APPENDIX 8**

No	Sex	Age	Years in Hospital	Level of Disability	ABS A TOTAL	ABS B TOTAL	Final Assessment
1	F	70	22	Mild	190	13	12 months
2	M	33	31	Severe	97	40	12 months
3	F	48	41	Severe	162	13	12 months
4	F	41	8	Borderline	237	49	12 months
5	F	31	20	Severe	42	59	12 months
6	M	32	28	Severe	99	55	18 months
7	M	35	21	Moderate	204	22	12 months
8	F	30	8	Moderate	185	30	18 months
9	F	48	20	Mild	193	4	12 months
10	M	42	21	Severe	151	22	18 months
11	M	55	16	Moderate	210	4	24 months
12	F	37	11	Moderate	132	21	30 months
13	F	39	7	Mild	201	18	24 months
14	F	57	20	Borderline	245	43	18 months
15	F	37	28	Moderate	172	11	24 months
16	F	32	19	Mild	203	45	24 months
17	F	61	14	Moderate	106	4	24 months
18	M	68	8	Mild	176	30	24 months
19	M	35	20	Moderate	190	10	24 months
20	M	37	20	Mild	205	18	12 months
21	M	37	5	Mild	268	9	6 months
22	M	25	19	Severe	131	23	24 months
23	M	30	12	Severe	200	34	24 months
24	M	35	18	Mild	227	51	30 months
25	M	33	19	Moderate	214	8	12 months
26	F	62	20	Mild	190	20	12 months
27	F	69	20	Moderate	244	6	24 months
28	F	24	15	Moderate	190	29	6 months
29	F	26	21	Moderate	146	26	12 months
30	F	26	21	Profound	57	13	30 months
31	F	54	15	Mild	116	1	30 months
32	M	32	19	Moderate	199	21	30 months
33	M	36	33	Moderate	65	19	30 months
34	M	31	25	Severe	70	24	30 months
35	M	36	30	Severe	78	28	30 months
36	M	65	14	Moderate	217	1	30 months
37	M	47	10	Severe	81	35	30 months
38	M	37	12	Moderate	215	1	30 months
39	M	31	30	Moderate	217	27	30 months
40	M	45	18	Moderate	174	14	30 months
41	M	47	27	Borderline	230	5	30 months
42	F	49	34	Mild	158	31	12 months
43	F	22	13	Mild	208	32	30 months
44	F	38	27	Moderate	183	13	30 months
45	F	40	35	Severe	186	27	24 months
46	M	57	13	Mild	217	8	30 months
47	M	40	28	Moderate	177	6	30 months
48	M	58	36	Mild	215	3	30 months
49	M	33	24	Moderate	193	20	12 months
50	M	45	30	Moderate	149	42	30 months

Appendix 9

Consent Form

Appendix 9

CARE IN THE COMMUNITY PROJECT - CONSENT TO PARTICIPATE
(TO BE READ OUT TO THE CLIENT)

I am going to read something out to you and I am going to ask you if you understand what I am saying. If you don't understand it, please tell me and I will try to explain it again.

I would like you to take part in a project that is trying to see if people change when living outside the hospital. (Do you understand what I've just said?)

To help me get to know you better, I will need to ask you questions and fill in forms. I will also need to ask the staff questions.

I think it would be a good idea to tell people who don't know you how well you do. If I do that, I promise not to use your name. (Do you understand what I've just said?)

Would you like to ask me any questions about what I have read out to you?

I, ..., agree to take part in the Care in the Community Project. I have understood what has been read out to me.

SIGNED ..... DATE .....

OR

I .....(NAME) .....(JOB TITLE)

have helped the above named person to understand this form to the best of his/her

ability and feel that he/she is willing to participate in the project.

SIGNED: ....

IN THE PRESENCE OF: .....

I also agree to two six monthly follow-ups. However, if I change my mind at this time I don't have to take any further part in the project.

Appendix 10

Adaptive Behaviour Scale

A A M D
ADAPTIVE BEHAVIOR SCALE
For Children and Adults
1974 Revision

Name _____ Special Identification _____
(last) (first)

Date _____ Sex: M F Date of Birth _____
(mo) (day) (year) (mo) (day) (year)

Name of person filling out Scale _____

Source of information and relationship to person being evaluated (such as "John Doe - Parent," or "Self - Physician") _____

Additional Information: _____

_____

This Scale consists of a number of statements which describe some of the ways people act in different situations. There are several ways of administering the Scale; these, and detailed scoring instructions, appear in the accompanying *Manual*.

Instructions for the second part of the Scale immediately precede the second half of this booklet.

INSTRUCTIONS FOR PART ONE

There are two kinds of items in the first part of the Scale. The first requires that you select only ONE of the several possible responses. For example:

[2] Eating in Public (Circle only ONE)

Orders complete meals in restuarants	3	
Orders simple meals like hamburgers or hot dogs	(2)	2
Orders soft drinks at soda fountain or canteen	1	
Does not order at public eating places	0	

Notice that the statements are arranged in order of difficulty: 3,2,1,0. Circle the one statement which best describes the *most difficult* task the person can usually manage. In this example, the individual being observed can order simple meals like hamburgers or hot dogs (2), but cannot order a complete dinner (3). Therefore, (2) is circled in the example above. In scoring, 2 is entered in the circle to the right.

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The second type of item asks you to check ALL statements which apply to the person. For example:

[4] Table Manners
(Check ALL statements which apply)

		8-number checked =
Swallows food without chewing	—	
Chews food with mouth open	✓	
Drops food on table or floor	—	
Uses napkin incorrectly or not at all	✓	(6)
Talks with mouth full	—	
Takes food off others' plates	—	
Eats too fast or too slow	—	
Plays in food with fingers	—	
None of the above	—	
Does not apply, e g , because he or she is completely dependent on others (If checked, enter "0" in the circle to the right)	—	

In the example above, the second and fourth items are checked to indicate that the person "chews food with mouth open" and "uses napkin incorrectly." In scoring, the number of items checked, 2, is subtracted from 8, and the item score, 6, is entered in the circle to the right. Most items do not, however, require this subtraction; instead, the number checked can be directly entered as the score. The statement "None of the above," which is included for administrative purposes only, is not to be counted in scoring here.

Some items may deal with behaviors that are clearly against local regulations, (e.g., use of the telephone), or behaviors that are not possible for a person to perform because the opportunity does not exist, (e.g., eating in restaurants is not possible for someone who is bedridden). In these instances, you must still complete your rating. Give the person credit for the item if you feel absolutely certain that he or she can and would perform the behavior without additional training had he or she the opportunity to do so. Write "AR" for "Against Regulations" or "HNO" for "Has No Opportunity" next to the rating made in these cases. These notations will not affect the eventual scoring of that item, but will contribute to the understanding and interpretation of the person's adaptive behavior and environment.

Please observe the following general rules in completing the Scale:

1. In items which specify "with help" or "with assistance" for completion of task, these mean with *direct physical assistance.*

2. Give the person credit for an item even if he or she needs verbal prompting or reminding to complete the task unless the item definitely states *"without prompting"* or *"without reminder."*

This Scale is prepared for general use. Therefore, some of the items may not be appropriate for your specific setting, but please do try to complete all of them.

PART ONE

I. INDEPENDENT FUNCTIONING

A. Eating

[1] Use of Table Utensils (Circle only ONE)

Uses knife and fork correctly and neatly	6
Uses table knife for cutting or spreading	5
Feeds self with spoon and fork - neatly	4
Feeds self with spoon and fork - considerable spilling	3
Feeds self with spoon - neatly	2
Feeds self with spoon - considerable spilling	1
Feeds self with fingers or must be fed	0

[2] Eating in Public (Circle only ONE)

Orders complete meals in restaurants	3
Orders simple meals like hamburgers or hot dogs	2
Orders soft drinks at soda fountain or canteen	1
Does not order at public eating places	0

[3] Drinking (Circle only ONE)

Drinks without spilling, holding glass in one hand	3
Drinks from cup or glass unassisted - neatly	2
Drinks from cup or glass unassisted considerable spilling	1
Does not drink from cup or glass unassisted	0

[4] Table Manners (Check ALL statements which apply)

Swallows food without chewing	___
Chews food with mouth open	___
Drops food on table or floor	___
Uses napkin incorrectly or not at all	___
Talks with mouth full	___
Takes food off others' plates	___
Eats too fast or too slow	___
Plays in food with fingers	___
None of the above	___
Does not apply, e.g., because he or she is bedfast, and/or has liquid food only. (If checked, enter "0" in the circle to the right.)	___

8-number checked =

A. Eating → ADD 1-4

B. Toilet Use

[5] Toilet Training (Circle only ONE)

Never has toilet accidents	4
Never has toilet accidents during the day	3
Occasionally has toilet accidents during the day	2
Frequently has toilet accidents during the day	1
Is not toilet trained at all	0

[6] Self-Care at Toilet
(Check ALL statements which apply)

Lowers pants at the toilet without help	___
Sits on toilet seat without help	___
Uses toilet tissue appropriately	___
Flushes toilet after use	___
Puts on clothes without help	___
Washes hands without help	___
None of the above	___

B. Toilet Use → ADD 5-6

C. Cleanliness

[7] Washing Hands and Face
(Check ALL statements which apply)

Washes hands with soap	___
Washes face with soap	___
Washes hands and face with water	___
Dries hands and face	___
None of the above	___

[8] Bathing (Circle only ONE)

Prepares and completes bathing unaided	6
Washes and dries self completely without prompting or helping	5
Washes and dries self reasonably well with prompting	4
Washes and dries self with help	3
Attempts to soap and wash self	2
Cooperates when being washed and dried by others	1
Makes no attempt to wash or dry self	0

[9] Personal Hygiene
(Check ALL statements which apply)

Has strong underarm odor	___
Does not change underwear regularly by self	___
Skin is often dirty if not assisted	___
Does not keep nails clean by self	___
None of the above	___
Does not apply, e.g., because he or she is completely dependent on others (If checked, enter "0" in the circle to the right.)	___

4-number checked =

[10] Tooth Brushing (Circle only ONE)

Applies toothpaste and brushes teeth with up and down motion	5
Applies toothpaste and brushes teeth	4
Brushes teeth without help, but cannot apply toothpaste	3
Brushes teeth with supervision	2
Cooperates in having teeth brushed	1
Makes no attempt to brush teeth	0

[11] **Menstruation** (Circle only ONE)
(For males, Circle "no menstruation")

No menstruation	5
Cares for self completely for menstruation without assistance or reminder	5
Cares for self reasonably well during menstruation	4
Helps in changing pads during menstruation	3
Indicates pad needs changing during menstruation	2
Indicates that menstruation had begun	1
Will not care for self or seek help during menstruation	0

C. *Cleanliness* ——— ADD 7-11

D. Appearance

[12] **Posture** (Check ALL statements which apply)

- Mouth hangs open ___
- Head hangs down ___
- Stomach sticks out because of posture ___
- Shoulders slumped forward and back bent ___
- Walks with toes out or toes in ___
- Walks with feet far apart ___
- Shuffles, drags, or stamps feet when walking ___
- Walks on tiptoes ___
- **None of the above** ___
- Does not apply, e g , because he or she is bedfast or non-ambulatory (If checked, enter "0" in the circle to the right)

8-number checked =

[13] **Clothing** (Check ALL statements which apply)

- Clothes do not fit properly if not assisted ___
- Wears torn or unpressed clothing if not prompted ___
- Rewears dirty or soiled clothing if not prompted ___
- Wears clashing color combinations if not prompted ___
- Does not know the difference between work shoes and dress shoes ___
- Does not choose different clothing for formal and informal occasions ___
- Does not wear special clothing for different weather conditions (raincoat, overshoes, etc.) ___
- **None of the above** ___
- Does not apply, e g , because he or she is completely dependent on others (If checked, enter "0" in the circle to the right)

7-number checked =

D. *Appearance* ——— ADD 12-13

E. Care of Clothing

[14] **Care of Clothing**
(Check ALL statements which apply)

- Wipes and polishes shoes when needed ___
- Puts clothes in drawer or chest neatly ___
- Sends clothes to laundry without being reminded ___
- Hangs up clothes without being reminded ___
- **None of the above** ___

E. *Care of Clothing* ——— ENTER 14

F. Dressing and Undressing

[15] **Dressing** (Circle only ONE)

Completely dresses self	5
Completely dresses self with verbal prompting only	4
Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help	3
Dresses self with help in pulling or putting on most clothes and fastening them	2
Cooperates when dressed by extending arms or legs	1
Must be dressed completely	0

[16] **Undressing at Appropriate Times**
(Circle only ONE)

Completely undresses self	5
Completely undresses self with verbal prompting only	4
Undresses self by unfastening (unzipping, unbuttoning, unsnapping) clothes with help and pulling or taking them off with verbal prompting	3
Undresses self with help in unfastening and pulling or taking off most clothes	2
Cooperates when undressed by extending arms or legs	1
Must be completely undressed	0

[17] **Shoes** (Check ALL statements with apply)

- Puts on shoes correctly without assistance ___
- Ties shoe laces without assistance ___
- Unties shoe laces without assistance ___
- Removes shoes without assistance ___
- **None of the above** ___

F. *Dressing and Undressing* ——— ADD 15-17

G. Travel

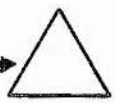
[18] **Sense of Direction** (Circle only ONE)

Goes a few blocks from hospital or school ground, or several blocks from home without getting lost	3
Goes around hospital ground or a few blocks from home without getting lost	2
Goes around cottage, ward, or home alone	1
Gets lost whenever leaving own living area	0

[19] Public Transportation
(Check ALL statements which apply)

Rides on train, long-distance bus or plane independently ___
Rides in taxi independently ___
Rides subway or city bus for unfamiliar journeys independently ___
Rides subway or city bus for familiar journeys independently ___
None of the above ___

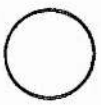
G. Travel → **ADD 18-19**



H. Other Independent Functioning

[20] Telephone (Check ALL statements which apply)

Uses telephone directory ___
Uses pay telephone ___
Makes telephone calls from private telephone ___
Answers telephone appropriately ___
Takes telephone messages ___
None of the above ___



[21] Miscellaneous Independent Functioning
(Check ALL statements which apply)

Prepares own bed at night ___
Goes to bed unassisted, e.g., getting in bed, covering with blanket, etc. ___
Has ordinary control of appetite, eats moderately ___
Knows postage rates, buys stamps from Post Office ___
Looks after personal health, e g , changes wet clothing ___
Deals with simple injuries, e.g., cuts, burns ___
Knows how and where to obtain a doctor's or dentist's help ___
Knows about welfare facilities in the community ___
None of the above ___

H. Other Independent Functioning → **ADD 20-21**

I. INDEPENDENT FUNCTIONING → **ADD TRIANGLES A-H**

II. PHYSICAL DEVELOPMENT

A. Sensory Development
(*Observable* functioning ability)

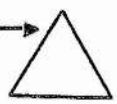
[22] Vision (With glasses, if used)
(Circle only ONE)

No difficulty in seeing 3
Some difficulty in seeing 2
Great difficulty in seeing 1
No vision at all 0

[23] Hearing (With hearing aid, if used)
(Circle only ONE)

No difficulty in hearing 3
Some difficulty in hearing 2
Great difficulty in hearing 1
No hearing at all 0

A. Sensory Development → **ADD 22-23**



B. Motor Development

[24] Body Balance (Circle only ONE)

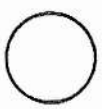
Stands on "tiptoe" for ten seconds if asked 5
Stands on one foot for two seconds if asked 4
Stands without support 3
Stands with support 2
Sits without support 1
Can do none of the above 0

[25] Walking and Running
(Check ALL statements which apply)

Walks alone ___
Walks up and down stairs alone ___
Walks down stairs by alternating feet ___
Runs without falling often ___
Hops, skips or jumps ___
None of the above ___

[26] Control of Hands
(Check ALL statements which apply)

Catches a ball ___
Throws a ball overhand ___
Lifts cup or glass ___
Grasps with thumb and finger ___
None of the above ___



[27] **Limb Function**
(Check ALL statements which apply)

Has effective use of right arm ____
Has effective use of left arm ____
Has effective use of right leg ____
Has effective use of left leg ____
None of the above ____

B. Motor Development → ADD 24-27

II. PHYSICAL DEVELOPMENT → ADD TRIANGLES A-B

[31] **Purchasing** (Circle only ONE)

Buys all own clothing	5
Buys own clothing accessories	4
Makes minor purchases without help (candy, soft drinks, etc.)	3
Does shopping with slight supervision	2
Does shopping with close supervision	1
Does no shopping	0

B. Shopping Skills → ADD 30-31

III. ECONOMIC ACTIVITY → ADD TRIANGLES A-B

III. ECONOMIC ACTIVITY

A. Money Handling and Budgeting

[28] **Money Handling** (Circle only ONE)

Uses banking facilities independently	4
Makes change correctly but does not use banking facilities	3
Adds coins of various denominations, up to one dollar	2
Uses money, but does not make change correctly	1
Does not use money	0

[29] **Budgeting**
(Check ALL statements which apply)

Saves money or tokens for a particular purpose ____
Budgets fares, meals, etc. ____
Spends money with some planning ____
Controls own major expenditures ____
None of the above ____

A. Money Handling and Budgeting → ADD 28-29

B. Shopping Skills

[30] **Errands** (Circle only ONE)

Goes to several shops and specifies different items	4
Goes to one shop and specifies one item	3
Goes on errands for simple purchasing without a note	2
Goes on errands for simple purchasing with a note	1
Cannot be sent on errands	0

IV. LANGUAGE DEVELOPMENT

A. Expression

[32] **Writing** (Circle only ONE)

Writes sensible and understandable letters	5
Writes short notes and memos	4
Writes or prints forty words	3
Writes or prints ten words	2
Writes or prints own name	1
Cannot write or print any words	0

[33] **Preverbal Expression**
(Check ALL statements which apply)

Nods head or smiles to express happiness ____
Indicates hunger ____
Indicates wants by pointing or vocal noises ____
Chuckles or laughs when happy ____
Expresses pleasure or anger by vocal noises ____
Is able to say at least a few words (Enter "6" if checked, regardless of other items.) ____
None of the above ____

[34] **Articulation** (Check ALL statements which apply--if no speech, check "None" and enter "0" in the circle)

4-number checked =

Speech is low, weak, whispered or difficult to hear ____
Speech is slowed, deliberate, or labored ____
Speech is hurried, accelerated, or pushed ____
Speaks with blocking, halting, or other irregular interruptions ____
None of the above ____

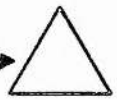
[35] **Sentences** (Circle only ONE)

Sometimes uses complex sentences containing "because," "but," etc.	3
Asks questions using words such as "why," "how," "what," etc	2
Speaks in simple sentences	1
Speaks in primitive phrases only, or is non-verbal	0

[36] **Word Usage** (Circle only ONE)

Talks about action when describing pictures	4
Names people or objects when describing pictures	3
Names familiar objects	2
Asks for things by their appropriate names	1
Is non-verbal or nearly non-verbal	0

A. Expression → ADD 32-36



B. Comprehension

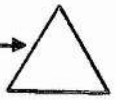
[37] **Reading** (Circle only ONE)

Reads books suitable for children nine years or older	5
Reads books suitable for children seven years old	4
Reads simple stories or comics	3
Reads various signs, e.g., "NO PARKING," "ONE WAY," "MEN," WOMEN," etc.	2
Recognizes ten or more words by sight	1
Recognizes fewer than ten words or none at all	0

[38] **Complex Instructions**
(Check ALL statements which apply)

Understands instructions containing prepositions, e.g., "on," "in," "behind," "under," etc.	___
Understands instructions referring to the order in which things must be done, e.g., "first do- then do-"	___
Understands instructions requiring a decision "If —, do this, but if not, do —"	___
None of the above ___	

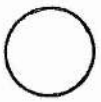
B. Comprehension → ADD 37-38



C. Social Language Development

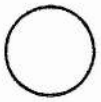
[39] **Conversation**
(Check ALL statements which apply)

Uses phrases such as "please," and "thank you"	___
Is sociable and talks during meals	___
Talks to others about sports, family, group activities, etc.	___
None of the above ___	

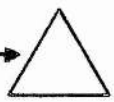


[40] **Miscellaneous Language Development**
(Check ALL statements which apply)

Can be reasoned with	___
Obviously responds when talked to	___
Talks sensibly	___
Reads books, newspapers, magazines for enjoyment	___
Repeats a story with little or no difficulty	___
Fills in the main items on application form reasonably well	___
None of the above ___	

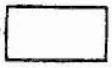


C. Social Language Development → ADD 39-40



IV. LANGUAGE DEVELOPMENT

ADD TRIANGLES A-C →



V. NUMBERS AND TIME

[41] **Numbers** (Circle only ONE)

Does simple addition and subtraction	5
Counts ten or more objects	4
Mechanically counts to ten	3
Counts two objects by saying "one, two"	2
Discriminates between "one" and "many" or "a lot"	1
Has no understanding of numbers	0

[42] **Time** (Check ALL statements which apply)

Tells time by clock or watch correctly to the minute ___
Understands time intervals, e.g., between "3 30" and "4:30" ___
Understands time equivalents, e.g., "9:15" is the same as "quarter past nine" ___
Associates time on clock with various actions and events ___
None of the above ___

[43] **Time Concept**
(Check ALL statements which apply)

Names the days of the week ___
Refers correctly to "morning" and "afternoon" ___
Understands difference between day-week, minute-hour, month-year, etc. ___
None of the above ___

V. NUMBERS AND TIME → ADD 41-43

VI. DOMESTIC ACTIVITY

A. Cleaning

[44] **Room Cleaning** (Circle only ONE)

Cleans room well, e.g., sweeping, dusting and tidying 2
Cleans room but not thoroughly 1
Does not clean room at all 0

[45] **Laundry** (Check ALL statements which apply)

Washes clothing ___
Dries clothing ___
Folds clothing ___
Irons clothing when appropriate ___
None of the above ___

A. Cleaning → ADD 44-45

B. Kitchen

[46] **Table Setting** (Circle only ONE)

Places all eating utensils, as well as napkins, salt, pepper, sugar, etc., in positions learned 3
Places plates, glasses, and utensils in positions learned 2
Places silver, plates, cups, etc., on the table 1
Does not set table at all 0

[47] **Food Preparation** (Circle only ONE)

Prepares an adequate complete meal (may use canned or frozen food) 3
Mixes and cooks simple food, e.g., fries eggs, makes pancakes, cooks TV dinners, etc. 2
Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc. 1
Does not prepare food at all 0

[48] **Table Clearing** (Circle only ONE)

Clears table of breakable dishes and glassware 2
Clears table of unbreakable dishes and silverware 1
Does not clear table at all 0

B. Kitchen → ADD 46-48

C. Other Domestic Activities

[49] **General Domestic Activity**
(Check ALL statements which apply)

Washes dishes well ___
Makes bed neatly ___
Helps with household chores when asked ___
Does household tasks routinely ___
None of the above ___

C. Other Domestic Activities → ENTER 49

VI. DOMESTIC ACTIVITY → ADD TRIANGLES A-C

VII. VOCATIONAL ACTIVITY

[50] **Job Complexity** (Circle only ONE)

Performs a job requiring use of tools or machinery, e.g., shop work, sewing, etc. 2
Performs simple work, e.g., simple gardening, mopping floors, emptying trash, etc 1
Performs no work at all 0

[51] **Job Performance**
(Check ALL statements which apply)
(If "0" is circled in item 50, check "None of the above" and enter "0" in the circle)

4-number checked =

Endangers others because of carelessness ___
Does not take care of tools ___
Is a very slow worker ___
Does sloppy, inaccurate work ___
None of the above ___

[52] **Work Habits**
(Check ALL statements which apply)
(If "0" is circled in item 50, check "None of the above" and enter "0" in the circle.)

5-number checked =

Is late from work without good reason ___
Is often absent from work ___
Does not complete jobs without constant encouragement ___
Leaves work station without permission ___
Grumbles or gripes about work ___
None of the above ___

VII. VOCATIONAL ACTIVITY → ADD 50-52 → ☐

VIII. SELF-DIRECTION

A. Initiative

[53] **Initiative** (Circle only ONE)

Initiates most of own activities, e.g., tasks, games, etc. 3
Asks if there is something to do, or explores surroundings, e.g., home, yard, etc 2
Will engage in activities only if assigned or directed 1
Will not engage in assigned activities, e.g., putting away toys, etc. 0

[54] **Passivity**
(Check ALL statements which apply)

6-number checked =

Has to be made to do things ___
Has no ambition ___
Seems to have no interest in things ___
Finishes task last because of wasted time ___
Is unnecessarily dependent on others for help ___
Movement is slow and sluggish ___
None of the above ___
Does not apply, e.g., because he or she is totally dependent on others (If checked, enter "0" in the circle to the right) ___

A. Initiative → ADD 53-54 → △

B. Perseverance

[55] **Attention** (Circle only ONE)

Will pay attention to purposeful activities for more than fifteen minutes, e.g., playing games, reading, cleaning up 4
Will pay attention to purposeful activities for at least fifteen minutes 3
Will pay attention to purposeful activities for at least ten minutes 2
Will pay attention to purposeful activities for at least five minutes 1
Will not pay attention to purposeful activities for as long as five minutes 0

[56] **Persistence**
(Check ALL statements which apply)

4-number checked =

Becomes easily discouraged ___
Fails to carry out tasks ___
Jumps from one activity to another ___
Needs constant encouragement to complete task ___
None of the above ___
Does not apply, e.g., because he or she is totally incapable of any organized activities (If checked, enter "0" in the circle to the right) ___

B. Perseverance → ADD 55-56 → △

C. Leisure Time

[57] **Leisure Time Activity**
(Check ALL statements which apply)

Organizes leisure time on a fairly complex level, e.g., plays billiards, fishes, etc. ___
Has hobby, e.g., painting, embroidery, collecting stamps or coins ___
Organizes leisure time adequately on a simple level, e.g., watching television, listening to phonograph, radio, etc ___
None of the above ___

C. Leisure Time → ENTER 57 → △

VIII. SELF-DIRECTION → ADD TRIANGLES A-C → ☐

IX. RESPONSIBILITY

[58] **Personal Belongings** (Circle only ONE)

Very dependable--always takes care of personal belongings 3
Usually dependable--usually takes care of personal belongings 2
Unreliable--seldom takes care of personal belongings 1
Not responsible at all--does not take care of personal belongings 0

[59] **General Responsibility** (Circle only ONE)

Very conscientious and assumes much responsibility--makes a special effort; the assigned activities are always performed 3
Usually dependable--makes an effort to carry out responsibility, one can be reasonably certain that the assigned activity will be performed 2
Unreliable--makes little effort to carry out responsibility; one is uncertain that the assigned activity will be performed 1
Not given responsibility, is unable to carry out responsibility at all 0

IX. RESPONSIBILITY ADD 58-59 ☐

X. SOCIALIZATION

[60] **Cooperation** (Circle only ONE)

Offers assistance to others 2
Is willing to help if asked 1
Never helps others 0

[61] **Consideration for Others**
(Check ALL statements which apply)

Shows interest in the affairs of others ___
Takes care of others' belongings ___
Directs or manages the affairs of others when needed ___
Shows consideration for others' feelings ___
None of the above ___

[62] **Awareness of Others**
(Check ALL statements which apply)

Recognizes own family ___
Recognizes people other than family ___
Has information about others, e.g., job, address, relation to self ___
Knows the names of people close to him, e.g., classmates, neighbors ___
Knows the names of people not regularly encountered ___
None of the above ___

[63] **Interaction With Others** (Circle only ONE)

Interacts with others in group games or activity 3
Interacts with others for at least a short period of time, e.g., showing or offering toys, clothing or objects 2
Interacts with others imitatively with little interaction 1
Does not respond to others in a socially acceptable manner 0

[64] **Participation in Group Activities**
(Circle only ONE)

Initiates group activities (leader and organizer) 3
Participates in group activities spontaneously and eagerly (active participant) 2
Participates in group activities if encouraged to do so (passive participant) 1
Does not participate in group activities 0

[65] **Selfishness**
(Check ALL statements which apply)

4-number checked =

Refuses to take turns ___
Does not share with others ___
Gets mad if he does not get his way ___
Interrupts aide or teacher who is helping another person ___
None of the above ___
Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the circle to the right) ___

[66] **Social Maturity**
(Check ALL statements which apply)

5-number checked =

Is too familiar with strangers ___
Is afraid of strangers ___
Does anything to make friends ___
Likes to hold hands with everyone ___
Is at someone's elbow constantly ___
None of the above ___
Does not apply, e.g., because he or she has no social interaction or is profoundly withdrawn. (If checked, enter "0" in the circle to the right.) ___

X. SOCIALIZATION ADD 60-66 ☐

INSTRUCTIONS FOR PART TWO

Part Two contains only one type of item. The following is an example.

[2] **Damages Personal Property**	**Occasionally**	**Frequently**	
Rips, tears, or chews own clothing	(1)	2	
Soils own property	1	(2)	(5)
Tears up own magazines, books, or other possessions	1	(2)	
Other (specify: _____)	1	2	
_____ **None of the above**	**Total** 1	4	

Select those of the statements which are true of the individual being evaluated, and circle (1) if the behavior occurs occasionally, or (2) if it occurs frequently. Check "None of the Above" where appropriate. In scoring, total each column on the bottom (Total) line, and enter the sum of these totals in the circle to the right. When "None of the above" is checked, enter 0 in the circle to the right. In the above example, the first statement is true occasionally, and the last two statements are true frequently; therefore, a score of 5 has been entered.

"Occasionally" signifies that the behavior occurs once in a while, or now and then, and "Frequently" signifies that the behavior occurs quite often, or habitually.

Use the space for "Other" when:

1. The person has related behavior problems *in addition* to those circled.
2. The person has behavior problems that are *not covered* by any of the examples listed.

The behavior listed under "Other" must be a specific example of the behavior problem stated in the item.

Some of the items in Part Two describe behaviors which need not be considered maladaptive for very young children (for example, pushing others). The question of whether a given behavior is adaptive or maladaptive depends on the way that particular behavior is viewed by people in our society. Nonetheless, in completing this Scale you are asked to record a person's behavior as accurately as possible, ignoring, for the moment, your personal biases; then, when you later interpret the impact of the reported behaviors, you should take into consideration societal attitudes.

PART TWO

I. VIOLENT AND DESTRUCTIVE BEHAVIOR

[1] Threatens or Does Physical Violence

	Occasionally	Frequently
Uses threatening gestures	1	2
Indirectly causes injury to others	1	2
Spits on others	1	2
Pushes, scratches or pinches others	1	2
Pulls others' hair, ears, etc.	1	2
Bites others	1	2
Kicks, strikes or slaps others	1	2
Throws objects at others	1	2
Chokes others	1	2
Uses objects as weapons against others	1	2
Hurts animals	1	2
Other (specify:_____)	1	2
None of the above	Total	

[2] Damages Personal Property

Rips, tears or chews own clothing	1	2
Soils own property	1	2
Tears up own magazines, books, or other possessions	1	2
Other (specify:_____)	1	2
None of the above	Total	

[3] Damages Others' Property

Rips, tears, or chews others' clothing	1	2
Soils others' property	1	2
Tears up others' magazines, books, or personal possessions	1	2
Other (specify:_____)	1	2
None of the above	Total	

[4] Damages Public Property

Tears up magazines, books or other public property	1	2
Is overly rough with furniture (kicks, mutilates, knocks it down)	1	2
Breaks windows	1	2
Stuffs toilet with paper, towels or other solid objects that cause an overflow	1	2
Attempts to set fires	1	2
Other (specify:_____)	1	2
None of the above	Total	

[5] Has Violent Temper, or Temper Tantrums

	Occasionally	Frequently
Cries and screams	1	2
Stamps feet while banging objects or slamming doors, etc.	1	2
Stamps feet, screaming and yelling	1	2
Throws self on floor, screaming and yelling	1	2
Other (specify:_____)	1	2
None of the above	Total	

I. VIOLENT AND DESTRUCTIVE BEHAVIOR → ADD 1-5 [ ]

II. ANTISOCIAL BEHAVIOR

[6] Teases or Gossips About Others

Gossips about others	1	2
Tells untrue or exaggerated stories about others	1	2
Teases others	1	2
Picks on others	1	2
Makes fun of others	1	2
Other (specify:_____)	1	2
None of the above	Total	

[7] Bosses and Manipulates Others

Tries to tell others what to do	1	2
Demands services from others	1	2
Pushes others around	1	2
Causes fights among other people	1	2
Manipulates others to get them in trouble	1	2
Other (specify:_____)	1	2
None of the above	Total	

[8] Disrupts Others' Activities

Is always in the way	1	2
Interferes with others' activities, e.g., by blocking passage, upsetting wheelchairs, etc	1	2
Upsets others' work	1	2
Knocks around articles that others are working with, e.g., puzzles, card games, etc.	1	2
Snatches things out of others' hands.	1	2
Other (specify:_____)	1	2
None of the above	Total	

Occasionally Frequently

[9] Is Inconsiderate of Others

Keeps temperature in public areas uncomfortable for others, e.g., opens or closes window, changes thermostat	1	2
Turns TV, radio or phonograph on too loudly	1	2
Makes loud noises while others are reading	1	2
Talks too loudly	1	2
Sprawls over furniture or space needed by others	1	2
Other (specify:_____)	1	2
None of the above	Total	

[10] Shows Disrespect for Others' Property

Does not return things that were borrowed	1	2
Uses others' property without permission	1	2
Loses others' belongings	1	2
Damages others' property	1	2
Does not recognize the difference between own and others' property	1	2
Other (specify:_____)	1	2
None of the above	Total	

[11] Uses Angry Language

Uses hostile language, e.g., "stupid jerk," "dirty pig," etc.	1	2
Swears, curses, or uses obscene language	1	2
Yells or screams threats of violence	1	2
Verbally threatens others, suggesting physical violence	1	2
Other (specify:_____)	1	2
None of the above	Total	

II. ANTISOCIAL BEHAVIOR

ADD 6-11 →

III. REBELLIOUS BEHAVIOR

Occasionally Frequently

[12] Ignores Regulations or Regular Routines

Has negative attitude toward rules but usually conforms	1	2
Has to be forced to go through waiting lines, e.g., lunch lines, ticket lines, etc.	1	2
Violates rules or regulations, e.g., eats in restricted areas, disobeys traffic signals, etc.	1	2
Refuses to participate in required activities, e.g., work, school, etc.	1	2
Other (specify:_____)	1	2
None of the above	Total	

[13] Resists Following Instructions, Requests or Orders

Gets upset if given a direct order	1	2
Plays deaf and does not follow instructions	1	2
Does not pay attention to instructions	1	2
Refuses to work on assigned subject	1	2
Hesitates for long periods before doing assigned tasks	1	2
Does the opposite of what was requested	1	2
Other (specify:_____)	1	2
None of the above	Total	

[14] Has Impudent or Rebellious Attitude Toward Authority

Resents persons in authority, e.g., teachers, group leaders, ward personnel, etc.	1	2
Is hostile toward people in authority	1	2
Mocks people in authority	1	2
Says that he can fire people in authority	1	2
Says relative will come to kill or harm persons in authority	1	2
Other (specify:_____)	1	2
None of the above	Total	

[15] Is Absent From, or Late For, the Proper Assignments or Places

Is late to required places or activities	1	2
Fails to return to places where he is supposed to be after leaving, e.g., going to toilet, running an errand, etc.	1	2
Leaves place of required activity without permission, e.g., work, class, etc.	1	2
Is absent from routine activities, e.g., work, class, etc.	1	2
Stays out late at night from home, hospital ward, dormitory, etc.	1	2
Other (specify:_____)	1	2
None of the above	Total	

Occasionally Frequently

16] Runs Away or Attempts to Run Away

Attempts to run away from hospital, home, or school ground	1	2
Runs away from group activities, e g , picnics, school buses, etc.	1	2
Runs away from hospital, home, or school ground	1	2
Other (specify _____)	1	2
_____None of the above	Total	

17] Misbehaves in Group Settings

Interrupts group discussion by talking about unrelated topics	1	2
Disrupts games by refusing to follow rules	1	2
Disrupts group activities by making loud noises or by acting up	1	2
Does not stay in seat during lesson period, lunch period, or other group sessions	1	2
Other (specify _____)	1	2
_____None of the above	Total	

II REBELLIOUS BEHAVIOR → ADD 12-17 [ ]

IV. UNTRUSTWORTHY BEHAVIOR

[18] Takes Others' Property Without Permission

Has been suspected of stealing	1	2
Takes others' belongings if not kept in place or locked	1	2
Takes others' belongings from pockets, purses, drawers, etc	1	2
Takes others' belongings by opening or breaking locks	1	2
Other (specify _____)	1	2
_____None of the above	Total	

[19] Lies or Cheats

Twists the truth to own advantage	1	2
Cheats in games, tests, assignments, etc	1	2
Lies about situations	1	2
Lies about self	1	2
Lies about others	1	2
Other (specify _____)	1	2
_____None of the above	Total	

V. UNTRUSTWORTHY BEHAVIOR → ADD 18-19 [ ]

V. WITHDRAWAL

Occasionally Frequently

[20] Is Inactive

Sits or stands in one position for a long period of time	1	2
Does nothing but sit and watch others	1	2
Falls asleep in a chair	1	2
Lies on the floor all day	1	2
Does not seem to react to anything	1	2
Other (specify _____)	1	2
_____None of the above	Total	

[21] Is Withdrawn

Seems unaware of surroundings	1	2
Is difficult to reach or contact	1	2
Is apathetic and unresponsive in feeling	1	2
Has a blank stare	1	2
Has a fixed expression	1	2
Other (specify _____)	1	2
_____None of the above	Total	

[22] Is Shy

Is timid and shy in social situations	1	2
Hides face in group situations, e g , parties, informal gatherings, etc.	1	2
Does not mix well with others	1	2
Prefers to be alone	1	2
Other (specify _____)	1	2
_____None of the above	Total	

V. WITHDRAWAL → ADD 20-22 [ ]

VI. STEREOTYPED BEHAVIOR AND ODD MANNERISMS

[23] Has Stereotyped Behaviors

Drums fingers	1	2
Taps feet continually	1	2
Has hands constantly in motion	1	2
Slaps, scratches, or rubs self continually	1	2
Waves or shakes parts of the body repeatedly	1	2
Moves or rolls head back and forth	1	2
Rocks body back and forth	1	2
Paces the floor	1	2
Other (specify _____)	1	2
_____None of the above	Total	

Occasionally Frequently

[24] Has Peculiar Posture or Odd Mannerisms

Holds head tilted	1	2
Sits with knees under chin	1	2
Walks on tiptoes	1	2
Lies on floor with feet up in the air	1	2
Walks with fingers in ears or with hands on head	1	2
Other (specify:_____)	1	2
None of the above	Total	

VI. STEREOTYPED BEHAVIOR AND ODD MANNERISMS

ADD 23-24 →

VII. INAPPROPRIATE INTERPERSONAL MANNERS

[25] Has Inappropriate Interpersonal Manners

Talks too close to others' faces	1	2
Blows on others' faces	1	2
Burps at others	1	2
Kisses or licks others	1	2
Hugs or squeezes others	1	2
Touches others inappropriately	1	2
Hangs on to others and does not let go	1	2
Other (specify:_____)	1	2
None of the above	Total	

VII. INAPPROPRIATE INTERPERSONAL MANNERS

ENTER 25 →

VIII. UNACCEPTABLE VOCAL HABITS

[26] Has Disturbing Vocal or Speech Habits

Giggles hysterically	1	2
Talks loudly or yells at others	1	2
Talks to self loudly	1	2
Laughs inappropriately	1	2
Makes growling, humming, or other unpleasant noises	1	2
Repeats a word or phrase over and over	1	2
Mimics others' speech	1	2
Other (specify:_____)	1	2
None of the above	Total	

VIII. UNACCEPTABLE VOCAL HABITS

ENTER 26 →

IX. UNACCEPTABLE OR ECCENTRIC HABITS

Occasionally Frequently

[27] Has Strange And Unacceptable Habits

Smells everything	1	2
Inappropriately stuffs things in pockets shirts, dresses or shoes	1	2
Pulls threads out of own clothing	1	2
Plays with things he is wearing, e.g., shoe string, buttons, etc.	1	2
Saves and wears unusual articles, e.g., safety pins, bottle caps, etc.	1	2
Hoards things, including foods	1	2
Plays with spit	1	2
Plays with feces or urine	1	2
Other (specify:_____)	1	2
None of the above	Total	

[28] Has Unacceptable Oral Habits

Drools	1	2
Grinds teeth audibly	1	2
Spits on the floor	1	2
Bites fingernails	1	2
Chews or sucks fingers or other parts of the body	1	2
Chews or sucks clothing or other inedibles	1	2
Eats inedibles	1	2
Drinks from toilet stool	1	2
Puts everything in mouth	1	2
Other (specify:_____)	1	2
None of the above	Total	

[29] Removes or Tears Off Own Clothing

Tears off buttons or zippers	1	2
Inappropriately removes shoes or socks	1	2
Undresses at the wrong times	1	2
Takes off all clothing while on the toilet	1	2
Tears off own clothing	1	2
Refuses to wear clothing	1	2
Other (specify:_____)	1	2
None of the above	Total	

Occasionally Frequently

[ ] Has Other Eccentric Habits and Tendencies

overly particular about places to sit or sleep	1	2
nds in a favorite spot, e g., by window, by door, etc	1	2
by anything that vibrates	1	2
afraid to climb stairs or to go down stairs	1	2
es not want to be touched	1	2
eams if touched	1	2
er (specify:_____)	1	2
____ None of the above		

Total

. UNACCEPTABLE OR ECCENTRIC HABITS — ADD 27-30 → ☐

X. SELF-ABUSIVE BEHAVIOR

[ ] Does Physical Violence to Self

es or cuts self	1	2
os or strikes self	1	2
gs head or other parts of the body against objects	1	2
s own hair, ears, etc.	1	2
atches or picks self causing injury	1	2
s and smears self	1	2
posely provokes abuse from others	1	2
s at any sores he might have	1	2
es objects in own ears, eyes, nose, or mouth	1	2
er (specify:_____)	1	2
____ None of the above		

Total

SELF-ABUSIVE BEHAVIOR — ENTER 31 → ☐

XI. HYPERACTIVE TENDENCIES

[ ] Has Hyperactive Tendencies

ks excessively	1	2
ll not sit still for any length of time	1	2
nstantly runs or jumps around the room or hall	1	2
ves or fidgets constantly	1	2
er (specify:_____)	1	2
____ None of the above		

Total

HYPERACTIVE TENDENCIES — ENTER 32 → ☐

XII. SEXUALLY ABERRANT BEHAVIOR

Occasionally Frequently

[33] Engages in Inappropriate Masturbation

Has attempted to masturbate openly	1	2
Masturbates in front of others	1	2
Masturbates in group	1	2
Other (specify:_____)	1	2
____ None of the above		

Total

[34] Exposes Body Improperly

Exposes body unnecessarily after using toilet	1	2
Stands in public places with pants down or with dress up	1	2
Exposes body excessively during activities, e g , playing, dancing, sitting, etc.	1	2
Undresses in public places, or in front of lighted windows	1	2
Other (specify:_____)	1	2
____ None of the above		

Total

[35] Has Homosexual Tendencies

Is sexually attracted to members of the same sex	1	2
Has approached others and attempted homosexual acts	1	2
Has engaged in homosexual activity	1	2
Other (specify:_____)	1	2
____ None of the above		

Total

[36] Sexual Behavior That Is Socially Unacceptable

Is overly seductive in appearance or actions	1	2
Hugs or caresses too intensely in public	1	2
Needs watching with regard to sexual behavior	1	2
Lifts or unbuttons others' clothing to touch intimately	1	2
Has sexual relations in public places	1	2
Is overly aggressive sexually	1	2
Has raped others	1	2
Is easily taken advantage of sexually	1	2
Other (specify:_____)	1	2
____ None of the above		

Total

XII. SEXUALLY ABERRANT BEHAVIOR — ADD 33-36 → ☐

XIII. PSYCHOLOGICAL DISTURBANCES

	Occasionally	Frequently
[37] Tends to Overestimate Own Abilities		
Does not recognize own limitations	1	2
Has too high an opinion of self	1	2
Talks about future plans that are unrealistic	1	2
Other (specify:_____)	1	2
None of the above	Total	

[38] Reacts Poorly to Criticism		
Does not talk when corrected	1	2
Withdraws or pouts when criticized	1	2
Becomes upset when criticized	1	2
Screams and cries when corrected	1	2
Other (specify:_____)	1	2
None of the above	Total	

[39] Reacts Poorly to Frustration		
Blames own mistakes on others	1	2
Withdraws or pouts when thwarted	1	2
Becomes upset when thwarted	1	2
Throws temper tantrums when does not get own way	1	2
Other (specify:_____)	1	2
None of the above	Total	

[40] Demands Excessive Attention or Praise		
Wants excessive praise	1	2
Is jealous of attention given to others	1	2
Demands excessive reassurance	1	2
Acts silly to gain attention	1	2
Other (specify:_____)	1	2
None of the above	Total	

[41] Seems To Feel Persecuted		
Complains of unfairness, even when equal shares or privileges have been given	1	2
Complains, "Nobody loves me"	1	2
Says, "Everybody picks on me"	1	2
Says, "People talk about me"	1	2
Says, "People are against me"	1	2
Acts suspicious of people	1	2
Other (specify:_____)	1	2
None of the above	Total	

	Occasionally	Frequently
[42] Has Hypochondriacal Tendencies		
Complains about imaginary physical ailments	1	2
Pretends to be ill	1	2
Acts sick after illness is over	1	2
Other (specify:_____)	1	2
None of the above	Total	

[43] Has Other Signs of Emotional Instabilities		
Changes mood without apparent reason	1	2
Complains of bad dreams	1	2
Cries out while asleep	1	2
Cries for no apparent reason	1	2
Seems to have no emotional control	1	2
Vomits when upset	1	2
Appears insecure or frightened in daily activities	1	2
Talks about people or things that cause unrealistic fears	1	2
Talks about suicide	1	2
Has made an attempt at suicide	1	2
Other (specify:_____)	1	2
None of the above	Total	

XIII. PSYCHOLOGICAL DISTURBANCES → ADD 37-43 [ ]

XIV. USE OF MEDICATIONS

[44] Use of Prescribed Medication		
Uses tranquilizers	1	2
Uses sedatives	1	2
Uses anticonvulsant drugs	1	2
Uses stimulants	1	2
Other (specify:_____)	1	2
None of the above	Total	

XIV. USE OF MEDICATIONS → ENTER 44 [ ]

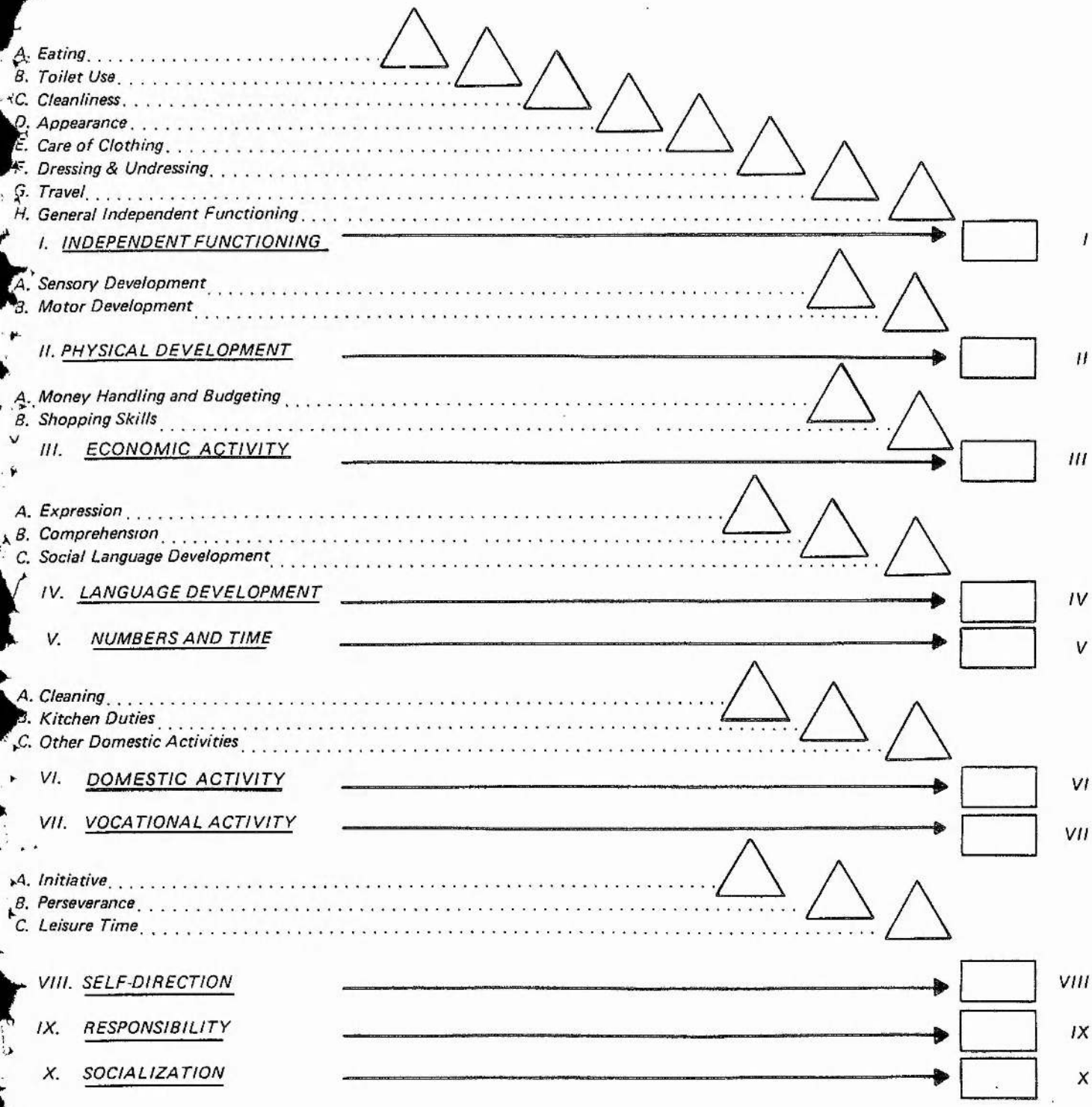
Identification _____

Age _____

Sex _____

Date of Administration _____

DATA SUMMARY SHEET - AAMD ADAPTIVE BEHAVIOR SCALE
PART ONE



DIRECT OBSERVATION OF COMMUNITY SKILLS

NAME ..... DATE ..... ASSESS NO. .....

DIRECT SKILLS ASSESSMENT

PEDESTRIAN CROSSING

Pushes button to activate crossing	[ ]
Waits on pavement	[ ]
Pays attention to light signal while waiting	[ ]
Starts crossing while green man is on & it is safe to	[ ]
Walks briskly over the crossing	[ ]
OVERALL	[_____]

ROAD CROSSING

Positions self so can see clearly and stops to check	[ ]
Looks both ways for traffic	[ ]
Acts appropriately for the situation	[ ]
Walks briskly across road	[ ]
Keeps looking around while crossing	[ ]
OVERALL	[_____]

CANTEEN

Knows where to order	[ ]
Ability to choose	[ ]
Ability to ask for what they want	[ ]
Use of please and thank-you	[ ]
Eye Contact	[ ]
Clarity of voice	[ ]
Confidence	[ ]
Ability to handle money	[ ]
Ability to carry tray	[ ]
Successfully collect trays, sugar, cutlery, etc	[ ]
OVERALL	[_____]

SHOPPING

Knows where to choose	[ ]
Ability to choose	[ ]
Knows where to pay	[ ]
Ability to handle money	[ ]
Clarity of voice	[ ]
Confidence	[ ]
OVERALL	[_____]

0	1	2	3	4	5	6
Very poor couldn't be worse	Low level of skill	Quite poor, mod aspects	Moderate level of skill	Quite good skills	Good skills	Excellent couldn't be better

BUS

PHONE

Ability to board bus	[ ]	Ability to lift receiver	[ ]
Ability to show pass/state fare	[ ]	Ability to insert money	[ ]
Ability to find seat	[ ]	Ability to dial	[ ]
Clarity of voice	[ ]	Ability to replace receiver	[ ]
Confidence	[ ]	Ability to collect change	[ ]
Eye contact	[ ]		
OVERALL	[_____]	OVERALL	[_____]

0	1	2	3	4	5	6
Very poor couldn't be worse	Low level of skill	Quite poor, mod aspects	Moderate level of skill	Quite good skills	Good skills	Excellent couldn't be better

Appendix 11

Direct Observation Of Community Skills

Appendix 12

Assessment of Confidence in Own Community Skills

ASSESSMENT OF CONFIDENCE IN OWN COMMUNITY SKILLS

NAME ..... DATE ..... ASSESS NO. .....

BUS TRAVEL

1. Would you feel nervous about travelling on a bus? Y/N
2. Would you know how to travel by Bus? Y/N
3. Would you feel nervious about travelling by bus if it was very busy? Y/N
4. Would you feel nervious about getting on a bus? Y/N
5. Would you be able to get on a bus? Y/N
6. Would you feel nervous about getting off the bus? Y/N
7. Would you be able to get off the bus okay? Y/N
8. Do you know how to stop the bus if you want to get off? Y/N
9. Would you feel nervous about stopping the bus? Y/N

ROAD CROSSING

1. Would you feel nervous about crossing the street? Y/N
2. Would you feel nervous about crossing the street if it was very busy? Y/N
3. Would you know how to use a green man crossing? Y/N
4. Would you feel nervous about using a green man crossing? Y/N
5. Would you feel nervous about being in a crowded street? Y/N
6. Would you know how to use a moving stairway? Y/N
7. Would you feel nervous about using a moving stairway? Y/N

COMPLIMENTS

1. Would you feel nervous about giving someone a compliment? Y/N
2. Would you know how to give someone a compliment? Y/N
3. Would you be embarrassed about giving a compliment? Y/N
4. If someone paid you a compliment, would you know what to do? Y/N

CAFETERIA SKILLS

1. Would you feel nervious about going to the cafe? Y/N
2. Would you feel nervous about going to the cafe if it was very busy? Y/N
3. Would you know where to go and order something in a cafe? Y/N
4. Would you be able to choose what you wanted to eat or drink in a cafe? Y/N
5. Would you feel nervous about choosing what you wanted to eat or drink? Y/N
6. Would you be able to ask the assistant for what you wanted? Y/N
7. Would you feel nervous about asking the assistant for what you wanted? Y/N
8. Would you be able to give the correct money and collect your change? Y/N
9. Would you feel nervous using money in a cafe? Y/N
10. Would you be able to find your way to a seat for the serving hatch? Y/N
11. If the cafe was very busy, would you ask if you could sit at someone else's table? Y/N
12. Would you feel nervous walking through the cafe with whatever you had ordered? Y/N

CONVERSATION

1. Would you feel nervous about talking to one person? Y/N
2. Would you feel nervous about talking to more than one person? Y/N
3. Would you know how to start talking to one person? Y/N
4. Would you know how to start talking to more than one person? Y/N
5. Would you know how to start talking to more than one person? Y/N
6. Would you feel nervous about asking one person questions? Y/N
7. Would you feel nervous about asking more that one person questions: Y/N
8. Would you know how to end a conversation? Y/N
9. Would you feel nervous about ending a conversation with one person? Y/N
10. Would you feel nervous about ending a conversation with more than one person? Y/N

STRANGERS

1. Would you know how to ask someone to go somewhere? Y/N
2. Would you feel nervous about asking a person to go someplace? Y/N
3. If someone asks you to go someplace and you do not want to go, would you know what to say? Y/N
4. If someone asks you to go someplace, would you feel nervous about saying you do not want to go? Y/N
5. If a stranger asks you to go somewhere, would you know what to say? Y/N
6. If a stranger asks you to go someplace, would you feel nervous about saying that you do not want to go? Y/N
7. If a stranger keeps asking you to go someplace, would you know what to do? Y/N
8. If a stranger keeps asking you to go someplace, would you feel nervous? Y/N
9. Would you feel too nervous to walk away? Y/N

PUB SKILLS

1. Would you feel nervous about going to the pub? Y/N
2. Would you feel nervous about going to the pub if it was very busy? Y/N
3. Would you know where to go to order a drink in a pub? Y/N
4. Would you be able to choose what to drink? Y/N
5. Would you feel nervous about choosing what to drink? Y/N
6. Would you be able to ask the person behind the bar for what you wanted? Y/N
7. Would you feel nervous about asking for what you wanted? Y/N
8. Would be able to give the correct money and collect your change? Y/N
9. Would using money in a pub make you feel nervous? Y/N

Appendix 13

Staff Rating Of Social Skills

STAFF RATING OF SOCIAL SKILLS

BASIC NON-VERBAL SKILLS

	1	2	3	4	5
FACIAL EXPRESSION	Extremely inappropriate Excessive glaring/grinning	Frequently inappropriate to situation	Little change with situation neutral / blank	Usually appropriate Occasional excess of frowning	Always appropriate to situation Relaxed
POSTURE	Extremely inappropriate Severe and continuous slouching etc.	Frequent slouching or excessive tense/rigid Tightly folded limbs	Posture sometimes too casual / tense	Usually appropriate but can be slightly too relaxed	Always appropriate Poised but relaxed. Arms down, back straight etc.
GESTURES	Total absence or severe excess of gestures	Frequent excessive or inadequate use. Gross hand movements	Moderately excessive or inadequate use	Slightly excessive or inadequate use	Uses gesture for emphasis / information appropriate
EYE CONTRACT	Total gaze aversion or continuous intense staring	Frequent gaze aversion or inappropriate staring	Moderate inadequacy or excessive staring	Usually appropriate Occasional avoidance or stares under stress	Always appropriate Used at intervals in conversation and as a cue for others

NON VERBAL RESPONSES

SOCIAL DISTANCE	Extremely inappropriate Always too close or too	Frequently too close or distant Makes others feel	Sometimes shows inappropriate distance	Usually appropriate May be less so when stressed	Always appropriate to the situation
FIDDLING MOVEMENTS	Extremely inappropriate movement, position shifting etc.	Frequent and excessive fidgeting	Excess of fiddling and fidgeting in conversation /under stress	Occasionally inappropriate e.g. fiddling with clothes during conversation	Always appropriate Shifts position as necessary
SMILING/ LAUGHING	Total absence or continuous inappropriate smiling	Rarely smiles in situations which cues smiling	Sometimes fails to smile when appropriate or smiles inappropriately	Usually appropriate Occasionally fails to smile when appropriate	Always appropriate e.g. in response to jokes
HEAD MOVEMENTS	Total absence of appropriate movements or continuous movement	Rarely uses appropriate head movements	Moderately inadequate or excessive use of head movements	Usually appropriate Slight under use of head movements	Always appropriate for agree/disagreeing when listening

QUALITY OF SPEECH

	1	2	3	4	5
AMOUNT SPOKEN	Extremely minimal Mostly one word brief statements Hardly speaks	Very minimal or excessive Monopolises the conversation	Moderate excess or inadequacy of speech	Usually appropriate Occasional slight excess of inadequacy	Always appropriate to situation Appropriate length and frequency of utterance
LATENCY OF RESPONSE	Always extremely slow in responding Abnormal delay	Frequently very slow in responding Makes others feel uncomfortable	Sometimes rather slow in response during conversations	May be slight delay, but infrequent and not very obvious. May rush/become muddled	Rapid response Formulates words quickly No obvious delay
HESITATIONS AND PAUSES	Frequently and excessive pauses, hesitations Extremely broken, hard to follow	Frequent moderately severe pauses or infrequent prolonged hesitations	Occasional moderate pauses or hesitations Flow hardly impaired	Speech usually unbroken but occasional minor pauses or hesitations	Speech flows well no obvious pauses or hesitations
DYSFLUENCY	Continuous severe probs e.g. stuttering uhmms v. diff to understand	Frequent dysfluencies quite hard to understand	Sometimes shows dysfluencies of moderate severity	Occasional slight dysfluencies particularly under stress	No obvious dysfluencies Speech easy to understand

CONTENT OF SPEECH

REPETITION	Excessive and inappropriate repetitions of statements / info during conversations	Frequent inappropriate repetitions	Sometimes repeats info/phrases when inappropriate	Repetitions usually only when appropriate Slight excess during excess clarification	Repeats only when appropriate
INTER-RUPTIONS	Very high frequency persistent and irritating butting in	Frequent inappropriate interruptions	Occasional inappropriate interruptions	Infrequent interruptions Usually allows others to finish	Never interrupts unless OK to do so Makes excusing comments
INTEREST CONTENT	Always extremely boring. Excessive talking about self	Often very boring Fails to select topics for listeners interest	Occasionally boring to listener	Usually quite interesting Selects topics to interest listener	Always interesting and informative
RELEVANCY	Always wanders off topic Extreme digressions Rapid topic switching	Frequently wanders off subject Discusses topics inappropriate to sit	Occasional inappropriate digressions irrelevant topics during conversations	Content usually relevant and appropriate v. occasional digressions	Always sticks to relevant and appropriate topics of conversation

LISTENING SKILLS

	1	2	3	4	5
PERSONAL SELF DISCLOSURE	Total absence of self disclosures or excessive extremely personal info.	Frequent lack or excess of personal disclosure May embarrass others	Moderate lack/excess of personal experience history, feelings etc.	Frequency and content usually appropriate Occasionally inadequate/ excessive	Always appropriate to situation makes others feel at ease as listener
QUESTION TYPE FEEDBACK	Total absence whilst other is speaking or questioning responses are inappropriate	Very low frequency of question type feedback or rarely appropriate	Sometimes provides such feedback but frequency inadequate	Slight inadequacy of appropriate feedback	High frequency of appropriate question type responses e.g. Oh? really? Did you?
REFLECTION	Total; absence of reflections in listening role	Very low frequency	Inadequate but occasional use of accurate reflections	Frequent use but tend to be slightly inaccurate	Frequency use of reflections appropriate to content of conversation
ACKNOWLED-GEMENTS	Total absence in listening role	very low frequency of acknowledging	Inadequate but occasional use	Frequent use but slight inadequacy	Frequent use of appropriate acknowledgeme nt e.g. mm, ah, I see

BASIC CONVERSATION SKILLS

LENGTH OF REPLY TO QUESTIONS	Always extremely brief. Usually one word	Usually very brief	Sometimes very brief or usually excessively long	Answers usually full and appropriate length but occasionally too long/short	Always full provides required info. May qualify /extend answers
INFORMATION CONTENT	Conversations always contain minimal info Usually related to topic	Usually contains minimal or inappropriate info.	Sometimes fails to provide adequate info.	Usually adequate and appropriate info.	Always contain useful and appropriate relevant info.
FREQUENCY OF QUESTION ASKING	Total absence	Infrequent extremely inadequate question asking	Moderate frequency. Not adequate	Usually high frequency when taking lead/major roles. Slightly inadequate	Frequency always appropriate to situation
FREQUENCY OF INITIATION	Total absence during conversation Fails to maintain conversation	Very low frequency Fails to maintain conv. in lead role other s feel	Moderate but inadequate frequency. Can lead to conv. breakdown	Usually high but occasional inadequacy e.g. with strangers	Always appropriate

Appendix 14

Staff Rating Of Interpersonal Skills

STAFF RATING OF INTERPERSONAL SKILLS

NAME: RESPONDENT:
DATE: LENGTH OF TIME KNOWN TO CLIENT:

	1	2	3	4	5
Has friends amongst peers	None	No close friend	One close friend	Several friends at least one	Many friends at least two good ones
Talks freely with peers	Never	Rarely	Sometimes	Usually	Always
Joins in activities with peers	Never	Rarely	Sometimes	Usually	Very often
Is bullied by others	Very often	Often	Sometimes	Rarely	Never
Will talk in group situations	Never	Rarely	Sometimes	Often	Very often
Avoids peer interaction	Always	Often	Sometimes	Rarely	Never
Becomes aggressive or loses temper when teased by peers	Always				
Will start up a conversation with peers appropriately	Never	Rarely	Sometimes	Often	Very often
Joins in activities with family / residents	Never	Rarely	Sometimes	Often	Very often
Initiates conversations with family / staff	Never	Rarely	Sometimes	Often	Very often
Approaches staff / family appropriately with requests/questions	Never	Rarely	Sometimes	Often	Very often

	1	2	3	4	5
Talks freely to family / staff about general topics	Never	Rarely	Sometimes	Often	Very often
Is verbally aggressive towards family / staff	Always	Often	Sometimes	Rarely	Never
Becomes angry when criticised by family / staff	Always	Usually	Sometimes	Rarely	Never
Refuses family / staff requests & instructions	Always	Often	Sometimes	Rarely	Never
Argues inappropriately with family / staff if prevented from doing something he/she wants to do	Always	Usually	Sometimes	Rarely	Never
Engages / disengages good eye contact appropriately in conversation	Very poor	Poor	Moderate	Good	Very good
Facial expression is appropriate to situation	Never	Rarely	Sometimes	Usually	Always
Response to questions	Very brief	Poor	Moderate	Adequate	Detailed
Posture	Very poor	Poor	Moderate	Good	Excellent
Uses tone and pitch for emphasis	Very poor	Poor	Moderate	Good	Very good
Clarity of speech	Very poor	Poor	Moderate	Good	Very good
Fidgets & fiddles with hands during conversations	All the time	Often	Sometimes	Rarely	Never

	1	2	3	4	5
Laughs and smiles appropriately	Never or continually grins	Rarely	Sometimes	Usually	Always
Fluency of speech	Extremely poor hesitate stutter	Very poor	Moderate	Good	Excellent

Please rate the above named on a 10 point scale of general social skills performance:

1 2 3 4 5 6 7 8 9 10

Extremely Poor Moderate Excellent

Appendix 15

Self Rating Of Interpersonal Skills

Appendix 15

SELF RATING INTERPERSONAL SKILLS

Name: ..... Date of Birth: ..... Age: .....
Date: ..... Questionnaire Administrator: .....

Read through the list carefully and ascertain whether or not the trainee has difficulty with the following problems.

DO YOU:

1.	Feel shy with strangers?	YES	NO
2.	Find it hard to make friends in a new place?	YES	NO
3.	Sometimes stammer or stutter when you talk?	YES	NO
4.	Find you don't have many friends?	YES	NO
5.	Find it hard to take orders?	YES	NO
6.	Feel that a lot of other people don't like you?	YES	NO
7.	Feel shy with the opposite sex?	YES	NO
8.	Wish that more people liked you?	YES	NO
9.	Find it hard to think of things to say to strangers?	YES	NO
10.	Find it hard to say you're sorry?	YES	NO
11.	Find it hard to go into a shop to ask for something?	YES	NO
12.	Find it hard to ask a member of staff for something you want?	YES	NO
13.	Get teased a lot?	YES	NO
14.	Not know what to say to people when you first meet them?	YES	NO
15.	Find you lose your temper easily?	YES	NO
16.	Get embarrassed easily?	YES	NO
17.	Have difficulty looking people in the eye when they are talking to you?	YES	NO
18.	Often butt in and interrupt people when they are talking?	YES	NO
19.	Often lose your temper when people tease you?	YES	NO
20.	Find it hard to stick up for yourself against others?	YES	NO
21.	Worry what you would say to a male / female if you want out with them?	YES	NO
22.	Feel awkward meeting new people?	YES	NO
23.	Find it hard to talk to people you know?	YES	NO
24.	Get bullied often by other people?	YES	NO
25.	Feel uncomfortable at parties or discos?	YES	NO
26.	Feel nervous with strangers?	YES	NO
27.	Find it hard to talk to males / females?	YES	NO
28.	Feel uncomfortable if you're the centre of attention in a group?	YES	NO
29.	Find you talk too much?	YES	NO
30.	Find it hard to make friends?	YES	NO

31.	Find you talk too loudly?	YES	NO
32.	Find it hard to ask for help if you have a problem?	YES	NO
33.	Often worry that you might make a fool of yourself in front of people?	YES	NO
34.	Wish you had more friends?	YES	NO
35.	Find it hard to ask other people if you can join them?	YES	NO
36.	Find it hard to talk in front of a lot of people?	YES	NO
37.	Find it hard to tell people if you don't understand what they have said?	YES	NO
38	Find it hard to keep a conversation going with s stranger?	YES	NO
39.	Find you talk too quietly?	YES	NO
40.	Find that other people can easily get you to do things that you don't want to do?	YES	NO

Appendix 16

General Health Questionnaire

GENERAL HEALTH QUESTIONNAIRE

GHQ-30

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks.* Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1	**– been able to concentrate on whatever you're doing?**	Better than usual	Same as usual	Less than usual	Much less than usual
2	**– lost much sleep over worry?**	Not at all	No more than usual	Rather more than usual	Much more than usual
3	**– been having restless, disturbed nights?**	Not at all	No more than usual	Rather more than usual	Much more than usual
4	**– been managing to keep yourself busy and occupied?**	More so than usual	Same as usual	Rather less than usual	Much less than usual
5	**– been getting out of the house as much as usual?**	More so than usual	Same as usual	Less than usual	Much less than usual
6	**– been managing as well as most people would in your shoes?**	Better than most	About the same	Rather less well	Much less well
7	**– felt on the whole you were doing things well?**	Better than usual	About the same	Less well than usual	Much less well
8	**– been satisfied with the way you've carried out your task?**	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
9	**– been able to feel warmth and affection for those near to you?**	Better than usual	About same as usual	Less well than usual	Much less well
10	**– been finding it easy to get on with other people?**	Better than usual	About same as usual	Less well than usual	Much less well
11	**– spent much time chatting with people?**	More time than usual	About same as usual	Less time than usual	Much less than usual
12	**– felt that you are playing a useful part in things?**	More so than usual	Same as usual	Less useful than usual	Much less useful
13	**– felt capable of making decisions about things?**	More so than usual	Same as usual	Less so than usual	Much less capable

PLEASE TURN OVER

Appendix 17

Zung Anxiety Scale

Appendix 17

ZUNG ANXIETY SCALE

		None/a little of the time	Some of the time	Good part of the time	Most of the time
1	I feel more nervous and anxious than usual	0	1	2	3
2	I feel afraid for no reason at all	0	1	2	3
3	I get upset easily or panicky	0	1	3	3
4	I feel like I'm falling apart/going to pieces	0	1	2	3
5	I feel everything is okay and nothing bad will happen	0	1	2	3
6	My arms and legs shake and tremble	0	1	2	3
7	I'm bothered by neck/back pain/headaches	0	1	2	3
8	I feel weak and get tired easily	0	1	2	3
9	I feel calm & can sit still easily	0	1	2	3
10	I can feel my hear beating fast	0	1	2	3
11	I get dizzy spells	0	1	2	3
12	I have fainting spells or feel like it	0	1	2	3
13	I can breathe in/out okay	0	1	2	3
14	I get numbness/tingling in my fingers/toes	0	1	2	3
15	I am bothered by stomach aches/indigestion	0	1	2	3
16	I have to empty my bladder often	0	1	2	3
17	My hands or dry and warm	0	1	2	3
18	My face gets hot/blushes	0	1	2	3
19	I fall asleep easily and get a good night's sleep	0	1	2	3
20	I have nightmares	0	1	2	3

Appendix 18

Zung Depression Scale

Appendix 18

ZUNG DEPRESSION SCALE

		Rarely/at no time > 1 day	A little some of the time 1-2 days	Moderate amount of time 3-4 days	Most of the time 5-7 days
1	I feel downhearted / sad	0	1	2	3
2	I feel best in the morning	0	1	2	3
3	I have crying spells or feel like it	0	1	3	3
4	I have trouble getting to sleep at night	0	1	2	3
5	I feel nobody care	0	1	2	3
6	I eat as much as before	0	1	2	3
7	I am loosing weight	0	1	2	3
8	I have trouble with constipation	0	1	2	3
9	My hear bests faster than usual	0	1	2	3
10	I get tired for no reason	0	1	2	3
11	My mind is as clear as it used to be	0	1	2	3
12	I wake up too early	0	1	2	3
13	I find it easy to do the things I used to	0	1	2	3
14	I'm restless / can't keep still	0	1	2	3
15	I am hopeful about the future	0	1	2	3
16	I am more irritable than usual	0	1	2	3
17	I make decisions easily	0	1	2	3
18	I feel quite guilty	0	1	2	3
19	I feel I'm useful / needed	0	1	2	3
20	My life is pretty full	0	1	2	3
21	I feel others would be better off if I were dead	0	1	2	3
22	I still enjoy the things I used to	0	1	2	3

Appendix 19

Eysenck Withers Personality Scale

Appendix 19

EYSENCK-WITHERS

REMEMBER TO ANSWER EACH QUESTION

1	Do you like plenty of excitement going on around you?	YES	NO
2	Do you worry about your health?	YES	NO
3	Do you nearly always have a quick answer when people talk to you?	YES	NO
4	Do ideas run through your head so that you cannot sleep?	YES	NO
5	Do you sometimes get cross?	YES	NO
6	Do you like practical jokes?	YES	NO
7	Do you ever feel "just miserable" for no good reason?	YES	NO
8	Are you rather lively?	YES	NO
9	Do lots of things annoy you?	YES	NO
10	As a child, did you always do as you were told?	YES	NO
11	Do you like doing things where you have to act quickly?	YES	NO
12	Do you worry about awful things that might happen?	YES	NO
13	Can you get a party going?	YES	NO
14	Do you get thumping in your heart?	YES	NO
15	Are there people you definitely do not like?	YES	NO
16	When you make new friends do you usually make the first move?	YES	NO
17	Have you often felt tired for no good reason?	YES	NO
18	Do you like telling jokes or funny stories to your friends?	YES	NO
19	Are you touchy about some things?	YES	NO
20	Have you ever told a lie?	YES	NO
21	Are you usually happy and cheerful?	YES	NO
22	Do you suffer from nerves?	YES	NO
23	Do you sometimes put off until tomorrow what you ought to do today?	YES	NO
24	Do you like mixing with people?	YES	NO
25	Do you often feel fed up?	YES	NO
26	Do you sometimes boast a little?	YES	NO

27	Do you like playing jokes on others?	YES	NO
28	Do you sometimes get so restless that you cannot sit in a chair long?	YES	NO
29	Can you usually let yourself go and enjoy yourself at a lively party?	YES	NO
30	Are your feelings rather easily hurt?	YES	NO
31	Are all your habits good ones?	YES	NO
32	Do you like going out a lot?	YES	NO
33	Do you worry for a long while if you feel you have made a fool of yourself?	YES	NO
34	Do other people think of you as being very lively?	YES	NO
35	Do you sometimes feel life is just not worth living?	YES	NO
36	Do you sometimes talk about things you know nothing about?	YES	NO
37	Do you usually feel fairly sure you can do the things you have to?	YES	NO
38	Are you often "lost in thought"?	YES	NO
39	Can you say the things you are thinking quickly?	YES	NO
40	Do you find it hard to get to sleep at night because you are worrying about things?	YES	NO
41	Have you ever been late for an appointment or work?	YES	NO
42	Do you usually feel if things go badly they will work out right in the end?	YES	NO
43	Do you often feel lonely?	YES	NO
44	Are you slow and unhurried in the way you move?	YES	NO
45	Do you sometimes sulk?	YES	NO
46	If you say you will do something, do you always keep your promise?	YES	NO
47	Do you often long for exciting things to happen?	YES	NO
48	Are you often troubled with guilty feelings?	YES	NO
49	Now and then, do you lose your temper and get angry?	YES	NO
50	Do you very much enjoy talking to people?	YES	NO
51	Do you get attacks of shaking and trembling?	YES	NO
52	Do you sometimes have thoughts you would not like others to know about?	YES	NO

Appendix 19

EYSENCK - WITHERS PERSONALITY INVENTORY

NAME: CONDITION:

DATE:

1	YES	NO	18	YES	NO	35	YES	NO
2	YES	NO	19	YES	NO	36	YES	NO
3	YES	NO	20	YES	NO	37	YES	NO
4	YES	NO	21	YES	NO	38	YES	NO
5	YES	NO	22	YES	NO	39	YES	NO
. 6	YES	NO	23	YES	NO	40	YES	NO
7	YES	NO	24	YES	NO	41	YES	NO
8	YES	NO	25	YES	NO	42	YES	NO
9	YES	NO	26	YES	NO	43	YES	NO
10	YES	NO	27	YES	NO	44	YES	NO
11	YES	NO	28	YES	NO	45	YES	NO
12	YES	NO	29	YES	NO	46	YES	NO
13	YES	NO	30	YES	NO	47	YES	NO
14	YES	NO	31	YES	NO	48	YES	NO
15	YES	NO	32	YES	NO	49	YES	NO
16	YES	NO	33	YES	NO	50	YES	NO
17	YES	NO	34	YES	NO	51	YES	NO
						52	YES	NO

Appendix 20

Morale and Life Satisfaction Scale

Client No.: .....
Informant: .....

MORALE & LIFE SATISFACTION

Where possible, researcher will interview the client, where not possible, a key worker advocate will represent them.

OPINIONS

1. Do you have any friends? Who are they?
(Record but do not code) _____

x	not applicable
0	not known / incoherent
1	No
2	Yes

2. How often do you see them? _____

0	Not known / incoherent
1	Less than monthly
2	Monthly or more
3	Weekly or more
4	Every day
x	Every day

3. Do you like the other people living here? _____

0	Not known / incoherent	)
1	No	)
2	Accepts - "it's all right"	) Rate for 3-6
3	Yes - positively likes	)
x	Not applicable	)

4. Do you like the staff (or key workers who visit you)?

_____
Is there one person you particularly like?
(Record but do not code)

5. Do you like your dayroom / sitting room? _____
(Prompt, ie the place where you can sit and watch TV)

6. Do you like your bedroom (or dormitory)? _____

If shares - Would you like a room on your own or do you like sharing? _____

7. If on own - Would you like to share a room or do you like being on your own? _____

x	Not applicable
0	Not known / incoherent / no answer
1	Want something different
2	Content with present arrangement

8. Is there somewhere you can go if you want to be by yourself? _____
Where is it?

0 Not known / incoherent / no answer
1 No
2 Yes
x Not applicable

9i. Do you go to the Social Training Unit, Activity Centre, _____
Industrial Training Unit? (Specify by name)
(Record by do not code)

9ii. Do you have enough to do? _____
(Record but do not code)

9iii. Do you enjoy going there? _____

0 Not known / incoherent / no answer
1 No
2 Accepts - "it's all right"
3 Yes - positively likes
x No applicable

9iv. What do you do there?
NB: DO NOT CODE - MAKE NOTES

10. What do you do in the evenings / weekends:
Prompt by giving examples if necessary.
List activities:
NB: DO NOT CODE - MAKE NOTES

i. Do you like doing that? _____

0 Not known / incoherent / no answer
1 No
2 Accepts - "it's all right"
3 Yes - positively likes
x No applicable

11. Is there anything you'd like to do in the evenings that
you can't do? _____
Specify: _____
_____

x Not applicable
0 Not known / incoherent / no answer
1 Yes
2 No

If yes, why can't you do it?

12. Do you like the grounds / garden area you live in? _____

- *x* Not applicable
- 1 No
- 2 Accepts - "it's all right"
- 3 Yes - positively likes

13. Do you want to stay here? _____

- 1 No
- 2 Accepts - "it's all right"
- 3 Yes - positively likes

14. Is there anything you don't like about this place/hospital? _____

- 0 Not known / incoherent / no answer
- 1 Yes
- 2 No
- *x* Not applicable

If yes, want: _____

_____

_____

15. What do you feel about moving to a hostel / group home / elsewhere? _____

- 0 Not known / incoherent / no answer
- 1 Doesn't want to move
- 2 Indifferent
- 3 Accepts that it would be all right
- 4 Positively wants to move
- *x* Not applicable

16. Do you remember when you lived at Lynebank? _____
If yes, would you like to go back to live there?)

- 1 Yes
- 2 No

If no - Code as not applicable (*x*)

Specify reason for above choice
(MAKE NOTES - DO NOT CODE)

17. What sort of place would you like to live in if you could choose? _____
(Prompt)

- 1 Hospital
- 2 Hostel or group home
- 3 Own family home
- 4 Own house / flat / room
- 5 Don't know

Appendix 21

Assessment Of Living Units

ASSESSMENT OF LIVING UNITS

NAME: **DATE:**
ADDRESS: **RESPONDENT:**
Length of time in Ward/House:

I FACILITIES

1. HOW CLOSE ARE LOCAL SHOPS?
   - Within 1 mile
   - 2-3 miles
   - 4-5 miles
   - Over 5 miles
   - Unknown

2. HOW CLOSE IS TRANSPORT? _____

3. HOW CLOSE ARE RECREATIONAL AND SOCIAL FACILITIES, eg PUBS, CINEMAS? _____

4. HOW MANY CLIENTS VISIT THE SHOPS AT ONE TIME?
   - Individually
   - 2-5
   - 6-10
   - Over 10
   - N/A
   - UK

   _____

5. HOW MANY CLIENTS USE PUBLIC TRANSPORT AT ONE TIME? _____

6. HOW MANY CLIENTS USE THE SOCIAL FACILITIES AT ONE TIME? _____

SPACE AND PRIVACY

7. HOW MANY RESIDENTS LIVE HERE? _____

8. HOW MANY BATHROOMS ARE THERE: _____

9. HOW MANY TOILETS HAVE DOORS? _____

10. HOW MANY TOILET DOORS LOCK? _____

11. HOW MANY TOILETS HAVE TOILET PAPER AT THIS MOMENT? _____

12. HOW MANY BATHS / SHOWERS ARE IN ONE BATHROOM? _____

13. IS THERE FREE ACCESS TO HAND BASINS? _____

14. DO CLIENTS BATHE ALONE?
    1. Yes
    2. No
    9. UK

15. IS THERE A SINGLE BEDROOM FOR EVERYONE WHO WANTS ONE? _____

16. DO ALL ROOMS HAVE CURTAINS / BLINDS: _____

17. DO THE RESIDENTS HAVE A SAY IN WHAT T.V. PROGRAMME IS ON? _____

18. IS THERE AN EASY CHAIR FOR EVERY PERSON? _____

19. IS THERE A WASTEPAPER BASKET IN EVERY ROOM? _____

FORMS OF ADDRESS

20. HOW DO STAFF ADDRESS EACH OTHER?
    Surname
    Christian Name
    Title (eg Nurse)
    Nickname
    Mr, Mrs, etc
    Other
    _____

21. HOW DO STAFF ADDRESS THE CLIENTS?) _____
    (as above)

II. PATTERNS OF DAILY LIFE

22. DOES A "LIGHTS OUT" POLICY EXIST? _____
    Yes
    No

PLANNING THE CLIENTS' TRAINING

23. WHO SELECTS GOALS AND OBJECTIVES FOR THE CLIENTS?

Nursing Staff	_____
Medical Staff	_____
Family	_____
Client	_____
Multi-disciplinary Team	_____
Residential Staff	_____
Others	_____

24. WHO HAS ACCESS TO THEM?

Professional Staff	_____
Family	_____
Client	_____

MEETINGS

25. HOW OFTEN ARE STAFF/ CLIENT MEETINGS HELD?) _____

26. HOW OFTEN ARE CLIENT) MEETINGS HELD? _____

PROMPTING INDEPENDENCE MOBILITY

27. IS THE WARD/HOUSE LOCKED?) _____

28. ARE THE KITCHENS LOCKED?) _____

29. ARE THE BATHROOMS LOCKED?) _____

30. ARE THE BEDROOMS LOCKED?) _____

31. ARE THE STAFF ROOMS LOCKED?) _____

1. Yes
2. No
9. UK

ENTERTAINMENT

32. HOW MANY CLIENTS GO ON HOLIDAY TOGETHER? _____
    1. 1-3
    2. 4-6
    3. 7-12
    4. Over 12

FINANCES

33. IS EACH CLIENT OR HIS/HER ADVOCATE, eg, LAWYER SHOWN ACCOUNTS OF CLIENTS FINANCES?
    Regularly _____
    Not at all _____

34. IS ADVICE READILY AVAILABLE TO CLIENTS REGARDING FINANCIAL AFFAIRS? _____

FOOD

35. IS THE LAST MAIN MEAL OF THE DAY BEFORE 5.30 PM? _____
    1. Yes
    2. No
    9. UK

36. DO STAFF MEMBERS EAT WITH CLIENTS: _____

37. WHO CHOOSES THE MEALS? _____
    1. Staff
    2. Clients
    8. Others
    9. UK

VISITORS AND CONTACT

38. ARE VISITORS OFFERED REFRESHMENTS? _____

39. ARE THE CLIENTS ABLE TO RECEIVE PHONE CALLS? _____

40. DO THE CLIENTS HAVE ACCESS TO A PHONE? _____

41. DO THE CLIENTS HAVE A PHONE FOR THEIR OWN USE: _____

    1. Yes
    2. No
    9. UK

42. WHEN CAN VISITORS COME TO SEE CLIENTS? _____

1. Any time
2. Any date at specified visiting hours
3. Certain days only
9. UK

43. ARE THERE FACILITIES TO PROVIDE OVERNIGHT ACCOMMODATION FOR FAMILY / FRIENDS? _____

1. Yes
2. No
9. UK

DECORATION

44. WHO IS CONSULTED WHEN CHOOSING DECORATIONS AND FURNISHINGS? _____

Nursing / Residential Staff
Clients
Specialist Staff
Managerial Staff
Others
UK

45. DOES THE FURNITURE AND DECORATIONS VARY FOR EACH INDIVIDUAL? _____

Appendix 22

Assessment Of Individual Lifestyle

ASSESSMENT OF INDIVIDUAL LIFESTYLE

NAME: ADDRESS:
DATE: RESPONDENT:
LENGTH OF TIME KNOW TO CLIENT:

STAFF / CLIENT CONTACT

1 How does the client address the staff ?
- Surname
- Christian Name
- Title e.g. Nurse
- Nickname
- Mr, Mrs etc.
- Not applicable ------

2 Do the staff have daily one to tone contact with the Client ? ------

3 For how long ?
- 1 Ten minutes or less
- 2 Ten minutes to one hour
- 3 Over one hour
- 9 UK ------

4 What is the main purpose of staff / client contact ?
- 1 Physical care
- 2 Social contact
- 3 Teaching skills
- 4 Giving instructions
- 5 Correction
- 6 General conversation
- 8 Other
- 9 UK ------

5 What is the next main purpose of staff client contact ?
(code as above) ------

6A Does the client have access to:		B Do staff have contact with	
Speech Therapist	------		------
Physiotherapist	------		------
ocial worker	------		------
Psychiatrist	------		------
Psychologist	------		------
GP	------		------
Community Nurse	------		------
Other	------		------
Unknown	------		------

7 How often does the client have contact with:

1 Speech Therapist	------	7 Community Nurse	------
2 Physiotherapist	------	8 Other	------
3 Social worker	------	9 Unknown	------
4 Psychiatrist	------		
5 Psychologist	------		
6 GP	------		

PATTERNS OF DAILY LIFE

8 With how many others does the client share a bedroom ------

9 What time does the client go to bed: 1=before 7pm
a) on weekdays ------ 2=7pm - 9pm
b) at weekends ----- 3=after 9pm

10 Does the client have a structure day placement ? -----
1=Y 2=N

11 Do staff have contact with the client's day service staff ? ------
1=Y 2=N

ASSESSING THE CLIENT'S NEEDS

12 Does the client have a written IPP ? ------
1=Y 2=N

PROMOTING INDEPENDENCE

13 Is the client allowed outwith the grounds of the residency alone ? ------
1=Y 2=N

14 Is the client allowed to cross roads alone ? ------
1=Y 2=N

ENTERTAINMENT

	A Does the client use / have access to :			B How often:
15	Public transport	------	1=Y	------
16	Disco/parties	------	2=N	------
17	Shows	------		------
18	Outings	------		------
19	Holidays	------		------
20	Social Clubs	------		------
21	Shops	------		------
22	Other	------		------

23 Is the clients birthday celebrated ? ------
1=Y 2=N

PERSONAL POSSESSIONS

Does the client have his/her own:

24	Personal effects	------	
25	Games	------	1=Y 2=N 3=N/A
26	Books	------	
27	Jewellery	------	
28	Radio/cassette	------	

29 Are there restrictions on the use of any of these ? ------
1=Y 2=N

30 Does the client buy his/her own clothes ? ------
1=Y 2=N

31 Does the client choose which clothes to wear ? ------
1=Y 2=N

DOES EACH CLIENT HAVE HIS/HER OWN AND SUFFICIENT:

32	Underclothing	------
33	Top clothing	------
34	Outdoor clothing	------
35	Footwear	------
36	Night clothing	------

37 Do clients have somewhere to store their personal items ? ------
1=Y 2=N

FOOD

38 Does the client help prepare meals ? ------
1=Y 2=N

39 Is the client allowed drinks / snacks between meals ? ------
1=Y 2=N

VISITORS AND CONTACT

40 Does the client make visits to family / friends ? ------
1=Y 2=N 9=UK

41 Does the client have visits by family / friends ? ------

1	Daily	2	At least weekly
3	At least monthly	4	Less than monthly
5	Never	9	UK ------

42 Did the client go on holiday with family / friends during the last year ?
1=Y 2=N -----

43 Has the client had any guests to stay the night in the last month ?
1=Y 2=N -----

44 Is the clients family regularly kept informed about his/her progress ?
1=Y 2=N -----

45 What is the main method of doing this ?

1	Letter	2	Telephone
3	Formal meetings	4	Informal meetings
5	Not applicable	8	Other

---

46 How often are drugs prescribed for the client, reviewed by a Doctor ?

1	Daily	2	Weekly
3	Monthly	4	Less than monthly
5	Never		

Appendix 23

Personal Appearance Checklist

Appendix 23

THE PERSONAL APPEARANCE CHECKLIST

Tidiness of clothing

- Markedly inappropriate - would be very noticeable in community ----------
- Acceptable (wide range) ----------
- Fit of clothing ----------
- Choice of clothing
  (in relation to age, convention and season) ----------
- Cleanliness (clothing and / or body) ----------
- Smell ----------
- Hair (for males also beard etc.) ----------
- Gait and / or posture (whatever the cause) ----------
- Bags or other objects habitually carried around inappropriately ----------

Dependent? ----------

Appendix 24

Study 3 Subjects' Individual Characteristics

SUBJECTS - INDIVIDUAL CHARACTERISTICS **APPENDIX 24**

No.	Sex	Age	Years in Hospital	Level of Disability	ABS A Total	ABS B Total	Final Assessment
1	M	33	25	Profound	97	47	6 months
2	F	25	19	Profound	49	55	12 months
3	F	53	36	Moderate	194	12	12 months
4	M	26	18	Severe	88	30	12 months
5	F	50	31	Mild	220	20	12 months
6	M	35	20	Moderate	186	35	12 months
7	F	24	17	Moderate	168	24	12 months
8	F	36	30	Moderate	193	7	24 months
9	F	52	26	Mild	210	8	12 months
10	F	37	21	Moderate	187	6	24 months
11	F	31	21	Moderate	207	20	24 months
12	F	36	21	Mild	194	12	24 months
13	F	66	20	Mild	207	7	24 months
14	M	27	18	Severe	204	6	24 months
15	M	30	29	Profound	48	94	24 months
16	M	26	22	Severe	83	52	24 months
17	F	31	26	Severe	149	35	24 months
18	F	24	18	Severe	50	45	24 months
19	M	26	17	Moderate	160	20	12 months
20	M	53	19	Moderate	126	10	6 months
21	F	38	20	Moderate	192	32	6 months
22	F	31	19	Moderate	148	12	6 months
23	M	38	20	Severe	121	5	24 months

Appendix 25

Study 3 Controls' Individual Characteristics

CONTROLS - INDIVIDUAL CHARACTERISTICS

APPENDIX 25

No.	Sex	Age	Years in Hospital	Level of Disability	ABS A Total	ABS B Total	Final Assessment
1	M	32	28	Severe	99	55	18 months
2	F	31	20	Severe	142	59	18 months
3	F	48	41	Severe	162	13	18 months
4	M	33	31	Severe	97	40	18 months
5	F	41	8	Borderline	237	49	18 months
6	M	42	21	Severe	151	22	18 months
7	F	30	8	Moderate	185	30	18 months
8	F	40	35	Severe	186	27	24 months
9	F	70	22	Mild	186	13	18 months
10	F	37	28	Moderate	172	11	18 months
11	F	32	19	Mild	203	45	18 months
12	F	39	7	Mild	201	18	24 months
13	F	61	14	Moderate	106	4	24 months
14	M	25	19	Severe	131	23	24 months
15	M	31	25	Severe	70	24	24 months
16	M	36	30	Severe	78	28	24 months
17	F	26	21	Profound	57	13	24 months
18	F	37	11	Moderate	132	21	24 months

Appendix 26

Publications